

IX. Project Abstract

Project Title: Integrated Services for Children with Special Health care Needs, Priority #5: The President's New Freedom Initiative: State Implementation Grants for Integrated Community Systems for CSHCN.

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Project Period: 3 years

PROBLEM: There is no forum within the state of Arizona to provide for information sharing, the development of joint projects, and cooperative grant applications for services for children and youth with special health care needs. A financial evaluation of the cost effectiveness of placing health screeners in various clinical settings, including school-based clinics and providing external care coordination.

GOALS AND OBJECTIVES:

A major goal is the creation a statewide forum where stakeholders from governmental and state agencies, as well as local, and community level providers, children and youth with special health care needs (c/yshcn), and their families can review activities of the various agencies and communities, plan needs assessments, and study alternative funding for services for children and youth with special health care needs within the state of Arizona. Several task-specific subcommittees will conduct needs assessments, develop educational materials, and provide input and evaluation of quality improvement activities. Each committee will involve youth with special health care needs and their families. Three groups will consist primarily of youth and families who will be charged with integrating the family perspective into every agency and community service organization. The second major goal of this proposal is to study the impact of providing screening and care coordination to different clinical settings, including school-based clinics with the intent of evaluating the cost-effectiveness of this service in reducing redundancy, enhancing access, and ensuring higher quality of care outcomes. The impact of insurance coverage will be evaluated in each of the clinical settings. The culmination of all of the activities will result in a white paper that will be sent to the governor.

METHODOLOGY: A Statewide Integration Task Force will coordinate multi-faceted activities throughout the state that involves c/yshcn, families, health care providers, state agencies and community organizations.

COORDINATION: We will coordinate with national centers as well as with state and local agencies, and children and youth with special needs and their families throughout the state.

EVALUATION: Process evaluation of the committee activities will focus on monitoring achievement of process and product objectives in accord with project timelines. Achievement of outcome objectives will be monitored through tracking the health outcomes of children and youth seen in the clinical settings.

X. PROGRAM NARRATIVE

I. Introduction

A. History and Future

Federal funding identified priorities for change in the health care delivery system for children and youth with special health care needs (c/yshcn) in 1980s. This funding was tied to specific needs and thereby projects to address those needs (medical home, screening, organization of services, fair reimbursement, and family roles). As is true in any system that has large, somewhat diverse, and as of yet undefined interconnections, bureaucracies grew up devoted to defending specific projects. This independence fostered competition for the federal dollar, but it also generated duplication of services, processes, tools, and data.

Initially the principles of community-based, family-centered care began to surface as a national focus at the Surgeon General's Workshop at the Children's Hospital of Philadelphia in 1982. Over the next 10 years there was a national goal to build systems of care for children with special health care needs and their families. The Federal Healthy and Ready to Work Interagency Workgroup was designed to improve coordination among federal and state agencies and advocacy groups in supporting youth with disabilities in transition to work and independence. This workgroup, built upon the Federal Supplemental Security Income (SSI)/Children with Special health Care Needs (CSHCN), formed in 1990 with an emphasis on improving the SSI claims intake process and looked to full integration of YSHCN into the workforce. In 1991, the National Healthy People 2000 objectives set a goal to establish these new systems of care in all 50 states by the year 2000. By 1996, the Healthy and Ready to Work initiative organized to promote a comprehensive system of care to assist children with special health care needs as they transitioned from pediatric to adult health care and to post-secondary education and/or employment. In 1999, the Maternal and Child Health Bureau published the "National Agenda for Children with Special Health Care Needs: Measuring Success." The six performance outcomes defined in the National Agenda continue to be the objectives we are striving to meet. With a change in political leadership, the Bush administration introduced the President's New Freedom Initiative that focused attention on community integration for people with disabilities, promoting programs that increased independent living skills, self-advocacy, enhanced education opportunities, and integration into the workforce.

In addition to these governmental and professional agendas, there was increasing energy being devoted to the development of coordinated comprehensive systems of care and supports that were family centered and community based. From this movement there developed strong advocacy and community development teams that began to take charge of their local communities.

Arizona is making significant strides at integration in some areas, but in some areas it is just making small baby steps. However, there is a climate of cooperation and change that may provide an opportunity for the Office for Children with Special Health Care Needs (OCSHCN) to provide leadership in the integration of service for c/yshcn. The current proposal consists of four separate and parallel projects. They consist of: 1) conducting a statewide needs assessment; 2) forming an working group of stakeholders throughout the state who will be involved in the design, delivery, evaluation, and receipt of services for children and youth with special health care needs; 3) an empirical study which will evaluate if the presence of an additional staff within a clinical setting will enhance the provision of early and continuous screening of all children in that setting for developmental delays, dental problems, behavioral health problems, and issues related to transition to adulthood; and if when there is an identified person, external to the clinical setting, who facilitates and monitors referrals, c/yshcn more readily receive needed service; and 5) an

independent financial analysis of the effects of the clinical care coordination study with recommendations on changes in funding for continuous and early screening and care coordination.

The proposed project extends over three years and is broken into four major components. During the first six months there will be numerous needs assessments conducted of systems and key informants. The second major component of the study will extend from the seventh month of the project through the eighteenth month and will consist of an empirical study of different ways of coordinating care from early and continuous screening through the coordination of all services required by a c/yshcn. The third year will be devoted to an independent financial analysis of the cost effectiveness of changing reimbursement strategies for early and continuous screening and care coordination for those requiring multiple services from multiple providers. Throughout the three years of the project, an Integrated Services Task Force and a series of special subcommittees will provide oversight and coordination of all of the tasks. They will be charged with integrating the needs assessment data, the results of the clinical study of care coordination, the findings of the specific subcommittees, and the financial analysis into a position paper that will be presented to the governor.

B. Environmental Assessment

Community Partnership Forum

In preparation for this grant proposal, the ADHS/OCSHCN convened a meeting of state agencies, private not-for-profit companies, health care providers, advocacy groups, and families to discuss the current state of activity in Arizona around services for children with special health care needs (the attendees are listed in Appendix B. The purpose of this work group was to identify: 1) current activities being conducted by each of the participants; 2) partners in the development, delivery, or evaluation of those activities; and 3) to identify any strategic initiatives that could be utilized as a working model of collaboration. Additionally the group was to identify gaps in the system as well as to identify any partners that should be included in future meetings. The following summarizes the activities around the six MCHB national performance measures.

Current Activities Described by Partnership Forum

Family/Professional Partnerships

Numerous agencies indicated they had formal mechanisms to allow for parents and professionals to communicate and plan activities that would foster better partnerships throughout the state. There is a significant amount of training going on throughout the state on families training of professionals, agencies training of their staff, and in two cases families sitting on hiring panels. However, only two agencies, ADHS/OCSHCN and Maricopa Medical Center indicated they had parent teams that were specifically devoted to Spanish-speaking parents. Only ADHS/OCSHCN mentioned specific teams that involved outreach to or training of Native American families or providers in these communities, although many groups mentioned the need to develop diverse family teams as part of their strategic plan. Many groups indicated a need to include in their strategic planning process mechanisms to ensure the sustainability of family involvement, family and community team development, and training on concepts of family/professional partnerships through the integration of these concepts/teams into the infrastructure of their organizations. The integration of educational involvement with the Community Teams was problematic for behavioral health. The lack of seasoned family/parent mentors was also a key strategic issue.

There were numerous surveys and trainings being conducted by agencies indicating that a consolidation of data collection and training might be cost-effective and increase the integration of results across a multitude of issues, departments, and agencies. A recommendation for a statewide warehouse/bulletin

board posting of training materials/training activities on family involvement, and family/professional partnerships would promote cross-fertilization of ideas and opportunities, as well as reduce the duplication of activities.

Medical Home

While several groups did reference the AAP definition of a medical home, there was some differences among the groups as to what, where, and how a medical home functioned. An example of this was seen in the confusion about the concept of care coordination and medical home with some groups referencing the formalizing of communication between multiple agencies involved in the provision of services to a child as a medical home. The difficulty in coordinating between primary care and carve outs was evidenced, and despite the fact that there was discussion regarding numerous communication forms, it did not appear there was a universally accepted form or consistent usage of any form. Creating and sustaining linkages between screening and medical homes was referenced on several occasions as was the need to investigate alternative reimbursement strategies for the activities required within a medical home, particularly medical homes with large numbers of c/y with special health care needs. Numerous agencies are providing training to parents, health care providers, agencies, etc. It was not clear that all of these trainings had the same focus or if they were available in languages other than English. Several groups referenced the need for training on, and implementation of, quality improvement methodologies for medical homes.

Health Insurance

There was some discussion about alternative funding mechanism such as capitation, but the discussion revolved more around the lack of reimbursement for developmental screening, coordination activities, and less conventional service delivery systems such as telemedicine. Some discussion involved the insurance products being developed that target the notch group of families making too much to qualify for public programs but they cannot afford or their employer does not offer health care coverage. Evaluation of these programs has not occurred with regard to impact, cost effectiveness, or satisfaction by members and providers.

Strategically there were several comments about addressing the comprehensiveness of private insurance coverage as related to c/yshcn (many cited examples of insufficient caps to allow for sufficient coverage of life-long illness or conditions). The integration of payment for many services now provided through carve outs (e.g., behavioral health services) or other providers (e.g., dental services) was needed, particularly in the private insurance plans. The lack of dental and vision services for Medicaid beneficiaries over the age of 18 years was found to be problematic, although specific plans/recommendations to address these coverage issues was not forthcoming. One specific recommendation involved providing on-line information/courses regarding health care financing for c/yshcn, their parents, and providers.

Early and Continuous Screening

Numerous systems were identified that provided screenings and numerous screening instruments were documented. Clearly there was no consensus on a standard instrumentation (e.g., PEDS, Ages and Stages, the Denver II, Healthy Steps), or even consensus on who (ages 0 to 3 years or 0 to 5 years, or both) or what needed screening (hearing, developmental delays, dental, behavioral health). The lack of a system of documenting for consistent retrieval and communicating the results of these screenings to agencies, providers, or others involved in the provision of necessary services was lacking. Behavioral Health is just in the process of developing and implementing a screening tool with planned implementation in 2005.

Strategically, there was consensus on the need to develop a set of consistent tools, a standard documentation and referral process, and the need for quality improvement activities to ensure that the system does reach all the children and youth within the state.

Easy to Use Community Systems

The Statewide Universal Application Initiative and the involvement of the ADHS/OCSHCN community development teams were the focal point of systems created to improve the ease of use. There are many departmental and community-specific activities underway to improve the ease of use of systems but there did not appear to be a methodology to make this information mainstream.

Strategically, almost everyone identified the need to have a database of projects and their outcomes available to agencies, providers, communities, and families to establish best practices. There was emphasis on increased involvement of c/yshcn and their families with different languages and culture.

Transition to Adulthood

Arizona has a Transition Leadership team that is already bringing many of the agencies and partners together to evaluate all aspects of transition from education, work, health, and financial issues. The State of Arizona responded to a national level request from the National Center on Secondary Education and Transition to send a team to Washington D.C. to join major governmental agencies, including the U.S. Departments of Education, Labor, Social Security Administration, and the Office of Employment and Disability Policy. This team, the Arizona Transition Leadership Team, representing a cross section of agencies and programs that are involved in the transitioning of students from school to work or further education, developed a state-specific action plan to address gaps in transition linkages and poor post school outcomes for youth with disabilities.

Other agencies such as the Department of Education and Children's Rehabilitative Services indicated they had formal mechanisms in place to require the initiation of a transition plan at age 14. However, the participants expressed a lack of knowledge among providers, youth, and their families on the issues related to transition to adulthood, specifically naming Behavioral Health Services, pediatricians, and youth and their families. Additional issues included the lack of adult providers willing or knowledgeable regarding specific heretofore exclusively pediatric conditions to accept the task of providing and coordinating the health care needs of this population.

Strategically, many agencies and other groups are planning on using youth as trainers and participants in the development of services for other youth who are in the process of transitioning. There was an expression of a need to have youth lead IEPs as well as to have integration of health care planning and educational needs for developmentally delayed youth. There were no plans to address the physician shortage.

The Arizona Department of Health Services, Office for Children with Special Health Care Needs participates in the Transition Leadership Team and is committed to the following issues developed by the team:

- Develop core principles surrounding improving results for Arizona Youth;
- Align Secondary and Post-secondary requirements regarding disability documentation, access, and accommodations;
- Align the "No Child Left behind" with full integration of persons with disabilities;

- Change educational practices to reflect and support research demonstrating that all youth, but especially students with disabilities, benefit from work experiences and perform better, if education is tied to real-world situations and life experiences based on student preferences and interests; and
- Design strategies to align the workforce development system with the employment needs of transitioning students with disabilities.

The first activity of this team was to conduct a needs assessment of the data that is currently available in the system and what these data tell about the systems and processes. Additionally, the team polled various agencies, non-profit groups, etc regarding the services that are available in the community.

Gaps in Service

- Behavioral health services were not well integrated with other services; behavioral health had its own network, parent support groups, and screening instruments.
- There was not a coherent plan to integrate youth and families into the systems of care development and evaluation.
- Screening was very well developed for children age 0-3 years, less so for children 0-5, and very inconsistent after the age of 5. There were few if any consistent screening processes available for adolescents.
- Transition to adulthood services were more focused on health care transition than education, employments, and health care coverage transition issues.
- Issues/activities related to incarcerated and foster care children and youth was not addressed.

Missing Partners

- There was an under-representation of minority and ethnically diverse populations; the only representation from the Native American community was the Native American Liaison from ADHS.
- The Arizona Department of Juvenile Corrections was identified as a partner that needed to be included in any statewide integration plan.
- There were numerous mentions of other organizations within the community that provided behavioral health support and services that were not included in this group.
- Other health care professional groups, in particular nursing, needed to be included.
- There was a suggestion to reach out to commercial insurance plans to include these organizations in the integration of services throughout the state.

C. Statewide Integration Task Force

The Partnership Forum made it very clear that there are multiple agencies, health care providers, professional organizations, advocacy groups, and c/yshcn and their families that are involved in projects throughout the state aimed at providing more efficacious care for c/yshcn and their families. However, there is not an overall statewide integration nor is there an overall evaluation of this information to determine which projects are effective in achieving the goals and objectives of 2010 and the MCHB National Performance Measures for c/yshcn. Additionally, there are many systems of care and information gathering that have been designed and implemented by these various groups; but the linkages between the c/yshcn, their families, and the agencies/organizations providing the services is not well articulated, easy to use, nor consistently effective in making and maintaining these connections.

To address this problem, ADHS/OCSHCN proposes the creation of a statewide Integration Task Force to define all of the projects currently being conducted in Arizona, to address the needs of c/yshcn, evaluate data from a variety of needs assessment projects, to design and evaluate the effectiveness of expanded

parent/professional partnerships, and to make a series of formal recommendations to the governor on changes in the system.

1. Statewide Integration Task Force Partners

- See Membership list in Appendix B for the complete Statewide Integration Team
- A Community Parent Leader from the Parent-Led Community Action Council, Dr. David Warne, MD from the Arizona State University, W. P. Carey School of Business, a representative of the AZ Juvenile Justice System, and representatives from Behavioral Health Family and youth support groups will be added to the Statewide Integration Task Force.
- Patti Hackett, MEd, Co-Director of Health and Ready to Work National Center will participate with the Statewide Integration Task Force, via a virtual advisory council, to provide expertise and resources in identifying issues for yshcn that were not surveyed as part of the National Survey of CSHCN and periodic review of related materials.

There will be five subcommittees that will focus on the initiatives consistent with the MCHB National Performance measures.

Education and Training Committee

The purpose of the Education and Training Committee is to provide organization to the diverse number and type of educational activities that occur throughout the state regarding the needs and services for c/yshcn and their families. The committee will be a clearinghouse for educational materials ensuring that the message is consistent and congruent with national standards. The committee will post the availability of educational materials on the ADHS/OCSHCN web site along with the appropriate contact person. It is thought that by pooling resources across a number of diverse agencies and programs, the material will be easier to use, more readily available, consistent in approach, and reduce any development duplication. The committee will also use the e-learning management system available through Arizona State University, in partnership with ADHS, to monitor utilization of the e-learning products.

Partners

Proposed membership: ADHS/OCSHCN, ADHS/BHS, Southwest Human Development, NAU/IHD, Raising Special Kids, Pilot Parents of Southern Arizona and their graduates Partners in Policy, the Governor's Council on Developmental Disabilities, AzAAP, Department of Education SELECT Program, Statewide Integration of Community Development team members, Health and Ready to Work National Center, Anu Partap, MD, Northern Arizona University Multidisciplinary Program, Maricopa County Junior College System (Nursing and Education Programs), and University of Arizona Medical School (Pediatric Residency Program and the Tele-Health Program)

Cultural Competency Committee

The Cultural Competency Committee is designed to provide oversight and recommendations to the Integration Task Force and all other subcommittees on the addition of members from other cultures, ensuring that educational materials and presentations are culturally appropriate and multi-linguistic, to the extent feasible. The role of this committee is to function as the voice for the traditionally under-represented and underserved; the representatives will be the Cultural Brokers to the Native American, the Black/African American, and Hispanic communities throughout Arizona.

The committee will be responsible for designing a survey to address the needs of children, youth, and families among minority groups. The cultural broker will define the best mechanism to obtain this information; surveys, interviews, etc.

The committee will interface with the National Center for Cultural Competency as well as state and local resources in recommending educational trainings/presentations, fact sheets, and other mechanisms to reach out to the minority citizenry of Arizona. Additionally, they will identify individuals within state and community based organizations to participate in the design of an integrated system of care for c/yshcn that is representative of the racial, ethnic, and cultural diversity within the state of Arizona

Partners

ADHS/OCSHCN (Jacquilyn Kay Cox, PhD, Principal Investigator; Gloria Payne ADHS/OCSHCN Sickle Cell Program Manager; Parent from the Southern Arizona Community Development Team), ADHS/BHS Coordinator for the Native American Suicide Prevention Coalition; ADHS/Native American Liaison (Michael Allison); AHCCCS/Medicaid, yshcn and their families, Inter-Tribal Council, Indian Health Service, Health Department and Educational staff from Native American communities within Arizona, Governor's Council on Spinal Cord Injuries and traumatic Brain Injury, AmeriTribes (Julie Brown), Mark Carroll, MD, IHS Telemedicine Program, Dr. David Warne, ASU/W.P. Carey School of Business, and David Carey with Arizona Bridge to Independent Living.

Community-Development Initiative

ADHS/OCSHCN has been working with the Governor's Office and other participating Arizona state agencies to promote the expansion of the Community Development approach within their agencies. The Governor approved a one-day Summit in the spring of 2005 in Phoenix to promote the benefit/advantages of other participating Arizona State agencies operationalizing the Community Development approach as a new way of doing business.

Parent-Led Community Action Council

The Parent-Led Community Action Council will be formed to create an oversight committee for all community development projects throughout the state and facilitate the cross training and mentoring using the parent-to-parent model. The ADHS/OCSHCN community teams will identify at a minimum one parent and one professional from each community to provide oversight and feedback regarding community-based activities.

Partners

Parent leaders and professional from the OCSHCN community action teams throughout Arizona; Parent leaders from c/yshcn and family advocacy organizations throughout the state of Arizona (Raising Special Kids, Pilot Parents of Arizona, Partners in Policy).

Youth Advisory Council

The purpose of the Youth Advisory Council is to ensure that the voice of youth with special health care needs is integrated into the design, implementation and evaluation of all the components of this application. Youth will participate in the Youth and Parent Leadership Institute learning to be better self-advocates as well as learning skills to allow them to effectively interface with local communities and state and federal agencies to effect positive change in the deliver of health care, educational services, financial services to yshcn.

Partners

ADHS/OCSHCN, ADHS/BHS, Governor's Council on Developmental Disabilities (Jamie Synder), Governor's Council for Spinal and Brain Injury (Ashleigh Turner), Community Teams, Partners in Policy Making Program, Youth Action Council, Family Voices (Kids as Self-Advocates Program), Healthy and Ready to Work, eight youth contracted with OCSHCN and have participated in the Youth/Parent Leadership Development Institute, Statewide Transition Leadership Team, Adolescent Health Coalition

Specialty Services Committee

The Specialty Services Committee is responsible for assessment and implementation of additional service options for geographically isolated communities. Additionally, the committee will identify barriers to specialty care and evaluate the potential for using Tele-Medicine to meet these needs.

Partners: ADHS/OCSHCN, Children's Rehabilitative Clinic Administrative and Clinical staff, University of Arizona's Telemedicine Program. IHS Telemedicine Program.

Quality Improvement Committee

The Quality Improvement Committee is responsible for designing and implementing quality indicators, a process to review the data on these indicators, and making recommendations for changes in processes to achieve benchmarks established by reviewing national standards.

The Arizona Department of Economic Security, Division of Developmental Disabilities (DDD) and the Institute for Human Development (IHD) at Northern Arizona University have received a grant from the Centers for Medicare & Medicaid Services to evaluate consumer-to-consumer methods of gathering information about the quality of the Division of Developmental Disability's Home and Community-based services. The Quality Improvement Committee will work jointly with the DDD/IHD committee to identify youth and family members as candidates for both of these committees to obtain information about the quality of services directly from the consumer. This consumer-to-consumer approach will offer consumers a more private way to share experiences and opinions about the services they have received. As appropriate, these committees will share information on interview training methodologies, data analysis, and aggregated results to facilitate a dissemination of best practices in quality improvement efforts involving youth and families.

Partners

ADHS/OCSHCN, ADHS/BHS, ADHS/Department of Oral Health, AHCCCS/Medicaid, Medical Home clinical staff, NAU/IHD, Peggy Stemmler, MD, President, Arizona Chapter of the AAP, Southwest Institute for Families and Children with Special Health Care Needs, Governor's Office for Children, Youth, and Families/State School Readiness Board, and yshcn and their families.

D. Care Coordination Study

1. Introduction

Over the last five years, The National Center for Medical Home Initiatives for Children with Special Needs, as part of the American Academy of Pediatrics, has driven the medical community to develop "medical homes" which are accessible, family-centered, coordinated, comprehensive, culturally competent, compassionate, and continuous. In particular, the mission of the National Center has been to work with physicians, health professionals, families, and other individuals to meet the objectives set forth in The President's New Freedom Initiative and Healthy People 2010, with a special emphasis on creating access to medical homes.

Since 2000, when the "medical home" training program, created by the National Center, was fully implemented across the country, a number of keys to success and possible barriers have been recorded.

These pivotal details were the result of work conducted by “state medical home teams”. In developing their programs and protocols, important lessons were learned. The National Center promotes these lessons as a means of achieving the ultimate underlying goal of the “medical home” philosophy: a global systems network.

The AAP further states that care should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a relationship of mutual responsibility and trust with them.

The Medical Home concept encompasses the attributes of primary care and serves to provide, either directly, or via referrals and networks, the entire range of services needed to promote healthy growth and development (Starfield, 1992). Although health insurance coverage and primary care are often thought to be synonymous, health care coverage is just one of many factors that influence adequacy of a medical home for youth. A system must be in place that allows youth to access and utilize care effectively.

The study of care coordination will involve two primary care physician practices in the Phoenix and Tucson area and a school-based clinic. The selection of these sites will be directed by the results of the needs assessment data from the SLAITS which showed that Hispanic families were the least likely to endorse many of the MCHB National Performance measures. This project will fund a full-time bilingual screener in each of these clinical settings who will provide screening for developmental delays, behavioral health problems, oral health conditions, and issues related to transitioning to adult systems of health care for every child or youth seen in each of the clinical settings. The addition of behavioral health issues and oral health was driven by the SLAITS data which indicated that these were the highest unmet needs of c/yshcn in Arizona. Those children or youth who screen positive for any of the aforementioned conditions will be referred to OCSHCN Care Coordinator(s) funded by this project. The role of the OCSHCN Care Coordinator position is to determine what community-based systems of care meet the families identified needs, assist the family with eligibility applications, verify eligibility, refer the family to the services, and maintain contact with the family during the transition to a permanent agency or organizational case manager. For those families who do not qualify for publicly funded programs, the OCSHCN Care Coordinator(s) will facilitate referrals to private providers, self-help groups, and other family support/advocacy groups.

2. Selection of the Pediatric Office Sites

Practices will be selected to be a Medical Home site based on their ability and willingness to meet the criteria set forth in our defined objectives. The Integrated Services Task Force will extend an invitation to two practices to participate as Medical Home sites based on the recommendations from the Quality Improvement Team, the Youth Action and Parent–Led Community Development Councils and OCSHCN staff. These selected sites must currently accept all forms of insurance, including our state Medicaid plans. Practices cannot have a current screener or care coordinator in their office. The practices chosen as a Medical Home site will not be awarded funds, but instead, will be provided a full time screener. They must be willing to incorporate the screening findings into the patients’ medical record and share results with the families. The Medical Home site will need to serve all children and adolescents, not just those with special health care needs. They will agree to use multiple methods of communication including web-based communication boards at the request of families with children who have been identified with positive screens. These sites will follow accepted practice for the Release of Information Forms and be HIPAA compliant.

3. Selection of School-Based Health Centers

School-based clinics were selected as a potential Medical Home or at least a significant adjunct to a non-school-based Medical Home. School-based clinics allow students to have immediate access to health care providers for whatever health problems they may have, which range from minor aches and scrapes to acute illnesses. For many students, the school-based clinic is the only source of medical care.

Arizona School-Based Health Centers delivered 28,903 medical visits to 15,657 Arizona children during the 2001-2002 school year. These comprehensive, low-cost services included prevention, well-child visits, immunizations, medical care for acute and chronic illness and injury, as well as the more traditional referral and follow-up. Of the 15,657 students who accessed the school-based clinics in 2002, 61% were between 5 and 11 years old, although the percentage of 12-18 year olds more than doubled from 2001 from 15% to 32%. Fifty-five percent of all visits were by female students and the students were primarily Hispanic (85%). The proportion of Hispanic students increase 7% over 2001 and 85% of the users in 2002 reported that Spanish was the predominate language spoken among family members.

Most of the children served by the school-based health clinics have no health insurance and have no true medical home. Seventy-nine percent of the visits to school-based clinics in 2002 were by children and youth who had no health insurance, 12% were by children covered by AHCCCS/Medicaid, and 2% were covered by other insurance, but the services provided by the school-based clinic were not reimbursed. The school-based clinics received reimbursement for 12% of the visits by students with AHCCCS/Medicaid and 5% for those students who had other insurance coverage. The percentage of uninsured children declined from 89% in 2001 to 79% in 2002 reflecting the expanded effort of the school-based clinics to expand services and secure reimbursement for uninsured children. Most school-based clinics are affiliated with a hospital-based outpatient department that provides on-call services and after-hours coverage when the school-based clinic is closed. This configuration not only offers a location for the child to go at times when the school clinic is not open, but the affiliated location is also available as a medical home for all family members.

Most school-based clinics are located in elementary schools; however, they are also located in middle and high schools. School-based clinics operate in more than 50 Arizona school districts. They are well represented in rural schools; 41% of the Arizona school-based clinics operate in rural Arizona. These clinics offer a viable access to health care in communities where there is a significant provider shortage and transportation to health care services may be problematic.

Parents accompanied their child on a visit to the school-based clinics 30% of the time in 2002. All of the clinics encourage parental involvement and parental consent is required before any services are provided. The clinics support the philosophy of the parent participating as a partner in the decision making process. An evaluation conducted of a large school-based clinic in Maricopa County in 2000 showed that 88% of the parents were very satisfied or mostly satisfied with the services received by their children. Most of the comments describing why the parents were satisfied had to do with how they and their children were treated by the staff.

While the school-based clinics may not provide the complete accessibility of a true medical home, they do represent an opportunity to make health available in a place where children and youth usually are: the school. Recent literature has shown that having a regular source of care is the only factor significantly associated with seeing a physician within one year; not race, ethnicity, family income, or the absence of insurance (Bartman, Moe, & D'Angelo 1997). Furthermore, adolescents with one regular source of care are much more likely to receive the indicated preventative care and much less likely to have received

emergency department care than comparable adolescents without a regular source of care (Ryan, Kang, & Starfield, 2001).

4. Screening

In previous Medical Home demonstration projects, there has not been a single person responsible for screening the children and youth presenting for other clinical services. At best, this clinical screen was left to the physician, or more probably to the parent to raise concerns about a specific behavior. This study will assess whether the continued presence of a screener will increase the number children identified as needing additional diagnostic or treatment interventions and whether this early identification will result in earlier and potentially more effective interventions.

5. Care Coordination

The OCSHCN Care Coordinator(s) will be responsible for communicating with the physician's office or school-based clinic on the process and outcome of any and all referrals. If and when a c/yshcn is found eligible for a funded service (i.e., Early Intervention Services) and a service coordinator within that organization has been assigned, the OCSHCN Care Coordinator(s) will formally transfer care coordination to that agency and will so indicate in the documentation forwarded to the Medical Home.

To facilitate real-time communication between all of the providers, the c/yshcn, and the families, a secure individual web-based bulletin board will be developed for each client. With signed Release of Information forms from the guardian/family, anyone involved in the care of a c/yshcn can communicate with the family and each other about the type, quality, outcome and satisfaction with services. This real-time communication should produce more timely identification of and interventions for any barriers to successful care.

All data collected from the office-based screens through the care coordination and placement within an agency will be collected and analyzed by the OCSHCN staff. Clinical information related to the results of the screenings and any referral and follow-up made by the care coordinator(s) will become part of the clinical record at the clinical site (either physician's office or school-based clinic).

Through our new Learning Management System families will have the opportunity to create a web-based electronic communication board. A family can identify the team of people they would like to include in their electronic coordination community. They may add or delete participants as needed. This secure partitioned group will only be available to those people given access by the family. Our system will allow us to design these "communities" to meet the needs of the families to assist them in improving the coordination of care for their c/yshcn.

We are currently surveying our community partners, families and providers to identify their technical capabilities and interest in using technology for learning and communicating to coordinate care for c/yshcn families. Simultaneously surveys are being conducted statewide with contractors and families in the WIC program; EMS providers; and physicians and county health agencies who partner with our state bio-terrorism program.

6. Improving Access to Care

The four regional Children's Rehabilitative Services clinics will conduct a statewide assessment to identify all pediatric specialty providers as well as non-physician medical providers, such as Nutritionists, Genetic Counselors, Speech Pathologists, etc. After completion of the needs assessment the four regional sites with ADHS-OCSHCN will develop a provider matrix to aid the discussion on how and where to expand

our telemedicine system for children/youth and their families to provide family-centered, community-based care in the most efficient and effective way.

Our Flagstaff clinic reaches 13 of Arizona's 21 federally recognized tribes, including the Navajo nation, which covers 18,119.2 square miles in Northeastern Arizona and the Bullhead City region in the Northwestern part of our state. In an effort to provide more community-based specialty care to these remote areas the Flagstaff Children's Health Center-CRS will work with the Page Hospital and the Bullhead City Community Hospital to help develop and enhance their telemedicine capabilities.

Many of the contracted specialty providers for the Flagstaff CRS clinics are from the Phoenix metropolitan area with a few from Tucson. Being a small town and given the shortage of pediatric specialists, it has been necessary to contract with physicians to travel to Flagstaff. Though telemedicine will not eliminate all physician travel it does offer opportunities to utilize this technology to decrease the expense and burden of travel for both physicians and patients/families.

7. Anticipated benefit of project

Based on information from parents and current service coordinators, the greatest difficulty parents of c/yshcn needs face is navigating the myriad (or paucity, as the case may be) of services, supports, and entitlements. They must identify appropriate services, complete sometimes-redundant application processes, and withstand numerous interviews and evaluations. The purpose of this study is to evaluate the efficiency of providing a single point of contact for families in gaining information and access to services for their children. This single source of contact will be the coordinator of all assessments, evaluations, referrals, and outcomes of referrals for the Medical Home. For youth confronted with the numerous options and challenges of entering an adult system of not just health care, but financial changes, educational opportunities, and job training, the OCSHCN will identify and work with other potential service providers/funding sources such as Social Security Administration, Vocational Rehabilitation, Arizona Long-term Care, etc. to identify all of the components of a transition plan.

Partners

ADHS/OCSHCN/Office of Oral Health/BHS, AzAAP, AZ School-Based Clinics, Medical Home/Screening site practitioners, Parent-Led Action Teams, Youth Advisory Council, Quality Improvement Team and the Statewide Integration Task Force

II. Needs Assessment

A. Overview of Arizona

According to the 2000 data from the U. S. Census Bureau, of the 5.4 million people living in Arizona, 3.4 million live in the Phoenix metropolitan area, known as Maricopa County. Very rapid population growth is occurring in Arizona. Current census data shows Maricopa County had the nation's second largest gain in the number of residents, eclipsed only by Los Angeles County. Despite this second place ranking, Maricopa County's growth rate is three times that of Los Angeles County's growth rate.

Arizona's racial demographic is changing dramatically; in 2000, 64% of Arizona's inhabitants were White, 25% were Hispanic, 5% were Native American, and 3% were Black/African American. Within these racial and ethnic groups, the most rapid change is occurring in the Hispanic communities. From 1980 to 2000, the Hispanic population of Phoenix quadrupled. Today, 90% of Arizona's Hispanic population, more than 1 million people, live in the metropolitan Phoenix area. Census data also shows an increase in socioeconomic barriers as a result of the population boom. One-fourth of Hispanic families live below the poverty level. Based on information from the Phoenix office of Raising Special Kids, a Phoenix based

organization serving c/yshcn and their families, reported that the Hispanic clients seen by their organization are typically young parents between the ages of 18-25 years. Ninety percent of the Hispanic clients are single women with a large extended family that is involved in caring for the child with special needs.

Native Americans in Arizona are also facing similar barriers. Arizona has the third largest Native American population behind California and Oklahoma. The Inter-Tribal Council of Arizona identifies 22 tribes residing in Arizona, comprising a Native American population of 255,879. According to the U.S. Census Bureau 2000 Arizona census, 3.7% of male Native American/Alaskan Natives between the ages of 5 and 15 years had one type of disability compared to 3.5% of females. This proportion increased dramatically for the older youth; 12.1% of males, age 15 to 20 years reported one type of disability compared to 9.1% of females in the same age group. This increase in disability among the older youth may indicate that risk factors in life style choices, accidents, etc. are strong contributory factors among Arizona's Native American youth. Approximately 18% of these tribal members reside on tribal lands while 82% of tribal members are considered urban. A significant proportion of Native American Arizonan face financial challenges; 38% of the Native American population lives below the federal poverty level. The Navajo Nation's unemployment rate is almost five times higher than the state's average, and rates for other tribal nations are three times higher than the state's average. Tribal members living on reservations receive their health care services through Indian Health Services, but tribal members living in urban areas have a confusing array of barriers when accessing federal programs for health care services, depending on how long they have been off the reservation.

With the large Hispanic and Native American population it is not surprising that in approximately 16% of the homes, the primary language is Spanish, and in 2% of Native American homes the language spoken is primarily a Native American dialect. This emphasizes the needs for strong cultural consideration in the development of an integrated system of care for children and youth with special health care needs.

B. National Survey of Children with Special Health Care Needs

The National Survey for Children with Special Health Care Needs (CSHCN), conducted as a module of the State and Local Area Integrated Telephone Survey (SLAITS), is a broad-based, ongoing surveillance system for tracking and monitoring the health and wellbeing of children and adults. The SLAITS is sponsored by the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS); and is funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administrations (HSRA). The National Survey of CSHCN was designed to produce national and state-specific prevalence estimates of c/yshcn, describe the type of services they need and use, assess aspects of the systems of care, and provide health care coverage estimates.

SLAITS was conducted from October 2000 to April 2001 as part of the National Immunization Program's large-scale random digit-dial telephone survey. In Arizona, there were 8,542 children screened from 4,276 households to identify 774 c/yshcn. The data presented here is weighted to yield state and national estimates.

The National Survey of CSHCN identified c/yshcn based on functional limitations and service needs. Children were classified as c/yshcn for the SLAITS based on having a medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer, and met one of the following criteria: there was a need for prescription medications; there was increased use of medical care, mental health, or educational services; there was a need for treatment/counseling for emotional, developmental, or behavioral problems; the child was limited or prevented in their ability to do things; or the child had a

need for special therapy. Seventy-three percent of the children screened qualified as a child with special needs based on the need for prescription medications, followed by 44% based on the increased use of medical care, mental health, or educational services; 31% because of a need for treatment/counseling for an emotional, developmental, or behavioral problem. Twenty-three percent of the screened children qualified as a c/yshcn based on the fact they were limited in their ability to do things and 13% qualified based on the need for a special therapy.

Table 1 (see Appendix A, Table 1) presents the descriptive statistics from the 2001 SLAITS data. The weighted SLAITS data indicates that approximately 11% of children and youth in Arizona between the ages of 0 and 17 years of age can be classified as having special health care needs; significantly lower than the 13% projected nationally. Numerically this percentage translates to 153,410 c/yshcn in the state of Arizona. The proportion of c/yshcn increases among older children and youth; 6% of the children below the age of 5 years report having special health care needs as compared to 15% of children and youth aged 12 to 17 years. This linear relationship between prevalence and increasing age was seen both locally and at the national level and may reflect increasing identification and/or the development of special health care needs with age. In all age groups, the proportion of c/yshcn was somewhat below the national figures. The prevalence of special needs among male and female c/yshcn was significantly lower in Arizona than nationally. There were significantly fewer respondents in Arizona who reported their family income as less than 200% of the federal poverty level (9%) than was reported nationally (14%). The proportion of children whose parents reported their race as either Black (16%) or multiracial (18%) were somewhat higher than nationally reported levels; however, the proportion of Native American/Alaskan Natives in Arizona (6%) was substantially lower than the national results (17%). This is a somewhat striking result, given the number of Native Americans that reside in Arizona and may reflect a lack of telephone access bias among Native Americans living in Arizona.

The measures that evaluated the insurance coverage for c/yshcn did not differ from the national figures except for the percentage of children and youth reporting that their insurance was not adequate (30% for Arizona and 34% nationally, a difference that was not statistically significant). However, specific questions about the adequacy of insurance coverage failed to reveal any unusual financial difficulties when compared to the national estimates. The parents of c/yshcn in Arizona were somewhat less likely than the national estimates to report having to pay more than \$1,000 per year in medical expenses (9% compared to 11% nationally); to have experienced financial problems due to the child's health needs (18% compared to 21% nationally); or to spend more than 11 hours per week providing or coordinating health care for the child (12% compared to 14% nationally).

The access to care indicators show that the proportion of c/yshcn that had unmet needs was somewhat higher in Arizona (19%) compared to national figures (18%). An analysis of the needs of children and youth in Arizona revealed the highest needs were for prescription medication (88%), dental services (74%), routine preventative care (70%), and specialist care (48%). The parent was asked if the identified needs were being met, and in this case the parents rated communication aids/devices (62%), mental health counseling (20%), and genetic counseling (20%) as the needs that were most likely to be unmet. In a separate question, more Arizonan parents with c/yshcn reported that they had problems getting a referral for specialty care (26%) compared to national figures (22%) which is somewhat consistent with the unmet needs of mental health counseling and genetic counseling.

C. MCHB National Performance Measures for CSHCN

National Performance Measure #1: Families of children and youth with special health care needs will partner in decision-making and will be satisfied with the services they receive.

Two questions comprise the partnership outcome measure in SLAITS: whether doctors make the family feel like a partner and whether the family is satisfied with the services received. Overall, Arizona parents of c/yshcn reported that this measure was achieved in 51% of the respondents compared to 58% nationally. The discrepancy was due largely to a much lower score among Arizonans on the overall satisfaction measure (54%) compared to national estimates (60%). To determine if there were specific variables that predicted dissatisfaction, a logistic regression was performed on the probability of a parent endorsing the outcome measure as related to a number of descriptive independent variables. Higher educational level of the mother and higher family income were significantly associated with an increase in the probability of the family member reporting that they partnered in decision-making and that they were satisfied with the services they received. While there was no significant effect of race, Hispanics were significantly less likely than non-Hispanics to report that they partnered in decision-making and were satisfied with the services they received.

Focus groups conducted with primarily Spanish-speaking parents in a southern Arizona community revealed that the language barrier may have been the cause of the dissatisfaction of Hispanic families. The lack of English proficiency on the part of the patient and family and a lack of Spanish proficiency on the part of the health care providers may create a distance between the families and the health care community. Families in the focus group reported many occasions where translation of medical information was left to a family member or the dietary/janitorial staff of a health care facility. They also reported that it was not uncommon for medical release forms to be available only in English and they signed these forms without benefit of any translation. This resulted in the Hispanic families in our focus group feeling marginalized and excluded from the decision-making process.

The remaining significant predictive variable may be somewhat counterintuitive; parents who reported that their child or youth had moderately severe problems were significantly more likely than those reporting less severe impairment to report not being a partner in the decision making process and not satisfied with the services received. There was not a significant relationship between having either mild or severe impairment and the outcome of this measure. One interpretation of this finding is that severely impaired children probably receive more time and attention from the health care profession due to the very nature of their severe disabilities. On the other hand, mild levels of severity may not set up expectations in the parents of needing a strong partnership and the parents may be satisfied with the services they receive. However, parents of children in the moderately severe range may have higher expectations of a partnership than the provider and these disparate expectations lead to dissatisfaction.

National Performance Measure #2: Children with special health care needs will receive coordinated ongoing care within a medical home.

Several questions in the SLAITS are combined to determine the degree of compliance with this performance measure, the exact questions and the resulting weighted percentage are presented in Appendix A, Table 1). Overall, just a little over one-half (51%) of family members of c/yshcn confirmed that their child received care in a medical home compared to 53% nationally. The largest proportion of parents reported that their c/yshcn had a usual source of care (91%). However, only 30% of families reported that there was professional care coordination when needed and the largest contributing factor to this lack of professional care coordination was that the physicians did not communicate well with other programs (25%), but they did communicate with one another (54%). Sixty-four percent of the families with c/yshcn reported their child received family centered care compared to 67% nationally.

The results of the logistic regression showed that being Black/African American, having other insurance coverage (neither public nor private), having a moderate to high severity of impairment, and having

special health care needs that change all of the time significantly increased the probability of a parent reporting that their child did *not* receive coordinated ongoing comprehensive care within a medical home. There were no significant predictors for endorsing the questions about having a medical home.

National Performance Measure #3: Families of c/yshcn will have adequate private and/or public insurance to pay for the services they need.

Gaps in insurance, especially if six months in duration, are among the six factors significantly associated with not using a regular source of care. In contrast, many common socio-demographic factors such as parental education and ethnicity are not associated with using a regular source of care in a year.

The rate of children without health insurance in Arizona remains one of the highest in the nation. According to the Kaiser Commission on Medicaid and the Uninsured, Arizona's rate of uninsured children is 17% compared to 12% nationally. Economic factors, rising health care costs, and state budget pressures threaten to push these rates even higher. However, the problem may be as simple as enrolling eligible children. The Children's Action Alliance, a child advocacy group based in Phoenix, claims that if Arizona enrolled all eligible children in existing public programs, Arizona would move from having the third highest rate of uninsured children in the country (just after Texas and Nevada) to having one of the best rates of insurance coverage for children.

St. Luke's Health Initiatives conducted an analysis of health insurance status in Arizona and defined some of the characteristics of the uninsured in Arizona. First, 71% of uninsured Arizonans have incomes below 200% of the federal poverty level making their ability to pay for even employer-based insurance limited. In addition, 38% of Arizonans live in families employed by small businesses (less than 50 employees). Most small businesses do not offer health insurance to employees because they believe they cannot afford coverage in today's market. In Arizona and nationwide, the uninsured are disproportionately people of color. In Arizona, the rate of uninsured Hispanics is 31% compared to black, non-Hispanics at 21% and white non-Hispanics at 12%.

Arizona has a lower rate of private health care coverage for children than the national rate; 61% of Arizonans children are covered through employer-based or individual insurance coverage compared to 64% nationally. Arizona also has a slightly lower rate of public health insurance coverage for children, 22% compared to 23% nationally (Kaiser Commission, 2002). The Urban Institute suggests that one-half of the 8 million U.S. children uninsured in 2002 were eligible for either Medicaid or SCHIP. Using this estimate, approximately 130,00 of the 267,880 uninsured children in Arizona could be enrolled in existing programs.

AHCCCS, the Arizona state Medicaid system is responsible for eligibility determination for KidsCare, Arizona's SCHIP program, the state Department of Economic Security handles the eligibility determination for AHCCCS/Medicaid. This separation, according the Children's Action Alliance, creates many organizational challenges and adds complexity and barriers to families obtaining health care coverage.

There are currently several initiatives in Arizona aimed at streamlining both the application process and the provision of low-cost alternatives for families that do not qualify for publicly funded programs. Health e-Arizona is a web-based electronic screening and application process for public health insurance. Initiated by El Rio Community Health center in Pima County in 2002, it is now used by most federally designated Community Health Centers throughout Arizona, as well as several hospitals. The electronic

submission process requires full information before submission resulting in approval rate of 66% of electronic application compared to 33% approved through the paper process.

P-CAP in Pima County and Healthcare Connect in Maricopa County are health care access programs offering discounted health care to those not eligible for public health insurance and unable to afford commercial insurance products. Utilizing a federal grant to provide additional funding, P-CAP has 8,000 patients enrolled and Maricopa County Healthcare Connect began enrolling members in June 2004.

National Performance Measure # 4: Children will be screened early and continuously for special health care needs.

The OCSHCN Sickle Cell Program staff contact parents immediately upon notification by the Newborn Screening Unit of a diagnosis of Sickle Cell Disease. The interface may be by telephone or face-to-face with the family. Staff maintain contact with parents up to three times a week during the first three months following diagnosis to ensure that parents understand the disease, and are encouraged to call with questions as they arise. Children's Rehabilitative Services (CRS) serves over 148 children. The OCSHCN will continue to monitor the timeliness with which children with positive diagnosis receive appropriate care for Sickle Cell disease and the results of the Family Survey will be shared with parents as part of a process to develop an action plan to address areas of concern.

CRS will develop strategies to improve the process through which families and youth receive information about transitioning out of CRS to help identify resources to continue with dietary regimen of youth receiving a formula for metabolic conditions.

National Performance Measure #5: Community-based systems of care will be organized so that families can use them easily.

The SLAITS contained only one question related to this performance measure: parents of c/yshcn were asked if services were organized for ease of use. Seventy-one percent of Arizonans said services were usually or always organized for easy use compared to 74% nationally. Parents of c/yshcn who reported having AHCCCS/Medicaid or KidsCare/SCHIP (the two forms of public insurance in Arizona) were significantly less likely to endorse the ease of use question than parents of c/yshcn with private insurance suggesting that families of c/yshcn that have public insurance may experience more difficulty finding, accessing, or committing to services than parents of c/yshcn with private insurance. Parents who reported their c/yshcn medical condition as moderate and changing only once in a while were also significantly less likely to endorse the ease of use question than were parents with c/yshcn who had less severe medical conditions and were usually stable. Again this is a consistent finding that parents of c/yshcn whose needs are less severe and variable may be underserved or at least not served to the level of their expectations. Parents with incomes above 200% of the FPL were significantly more likely to endorse the ease of use question than were parents of c/yshcn that lived below 100% of the FPL suggesting that parents of c/yshcn that have higher incomes may be able to overcome barriers such as out-of-pocket costs and transportation needs to search and find services.

National Performance Measure #6: Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

1. National Data on Transition to Adulthood

The Robert Wood Johnson Foundation, in collaboration with the Foundation for Accountability, conducted a web-based survey of 2,000 adolescents, ages 13 to 17 in May 2001 as part of the Robert Wood Johnson Foundation National Strategic Indicators Project. They sought to learn from teens how interventions, particularly those provided by health care providers, helped teens through their transition to adulthood. This study included a group of teens with special health care needs, defined as those with "a

chronic physical, mental, emotional, or behavioral condition for which they experienced significant functioning problems and/or that required health and health-related services of an amount and type beyond that required by teens generally.” Forty-one percent of adolescents classified as having a special health care need reported engaging in one or more risky behaviors, i.e., smoking, alcohol, drug use within the last month or carrying a weapon for protection within the last year, compared to 32% of adolescents without a special health care need. A striking 39% of teens with special health care needs reported experiencing symptoms of depression within the last year compared to only 18% of children without a special health care need.

Teens with special health care needs were less likely to report engaging in regular exercise; 56% of yshcn reported engaging in regular exercise compared to 66% without a special health care need. In contrast, teens with special health care needs tend to associate with other teens that engage in risky behaviors. While teens with a special health care need reported seeing a health care provider 2.5 times more frequently than teens that did not have chronic medical conditions, 44% of teens with a special health care need reported problems getting services compared to 33% of teens without special health care needs. Also, teens with a special health care need reported that they were more likely to talk openly with their health care providers (59%) than teens experiencing symptoms of depression (48%) or teens engaged in risky behaviors (55%). Teens with special health care needs reported the lowest frequency of receiving dental services (74%) compared to teens without a special health care need (78%).

Based on these data, the authors of the study recommended that the health care system must commit to early identification and the provision of preventative screening and counseling services. Also, the system must commit to asking about difficult topics such as depression, smoking, and alcohol use. Physicians must take the time to have private and confidential health care visits with teenage patients.

2. *SLAITS Data on Transition*

The data from the SLAITS on questions surrounding issues of transition did not achieve a sufficient sample size to draw statistical conclusions for the state of Arizona.

3. *Arizona Data on Transition to Adulthood*

Arizona has 233 school districts, 5 tribal schools, and 47 Bureau of Indian Affairs Schools and 139,984 children with disabilities enrolled in special education. Information available from the Data Analysis System (DANS), at the Office of Special Education Programs, indicates only 50% of Arizona’s students with disabilities exit special education with a diploma. This figure places Arizona below the national baseline for educational outcomes. Earning a high school diploma is a basic educational achievement, and such low levels of achievement offer a stark reminder of the need to plan for long-term educational outcomes for youth with disabilities. The second National Longitudinal Transition Study, currently in progress, reports that only about 12% of students are participating in transition planning. Based on a needs assessment conducted by Raising Special Kids in Arizona, it was found that parents and schools reported not knowing how to find sources of information, support, and training in special education.

The following data from the Arizona Department of Education shows that:

- Three years after school exit, less than 10% of special education graduates are living above the poverty level;
- Twenty seven percent (27%) of students with disabilities, based on school data submission, drop out of Arizona schools;
- Nationally, the proportion of youth that went onto post-secondary education has risen 4.1%, but in Arizona the rate has dropped by 9.4%;

- There has been a 15% decline in students enrolled in vocational education classes, yet research explicitly states that student participation in as few as one vocational opportunity, increases graduation rates, employment rates, and the ability to earn a higher wage;
- The number of students having involvement with Vocational Rehabilitation is only 14% nationally; and it is assumed that the figure is lower in Arizona, although exact numbers are unavailable.

III. METHODOLOGY

Goals and Objectives

Goal 1. Create a statewide forum where stakeholders from governmental and state agencies, as well as local, and community level providers, YSHCN, and their families can review activities of the various agencies and communities, plan needs assessments, and study alternative funding for services for c/yshcn within the state of Arizona.

Objective 1.1. Create a Statewide Integration Task Force to evaluate programs/services for c/yshcn in Arizona by June 2005.

Activity 1.1.1. Solicit letters of support from the membership to include in the grant proposal.

Activity 1.1.2. Circulate final copy of the grant proposal to membership for review and comment.

Activity 1.1.3. Convene second meeting following grant award to discuss structure, planning activities, meeting schedule, and outcomes.

Objective 1.2. Develop an action plan of activities and accountabilities for all members of the Task Force.

Activity 1.2.1. Select a planning committee to complete the plan by August 2005.

Activity 1.2.2. Circulate planning document to membership by September 2005.

Objective 1.3. Identify key activities of individual agencies and community partners to partner in the development, implementation, and/or expansion of these activities by August 2005.

Activity 1.3.1. Obtain a more comprehensive list of current projects in each members environment, the degree to which these projects impact or serve c/yshcn, how they are funded, and obtain any descriptive or outcome data associated with the programs/services.

Activity 1.3.2. With permission of the members, post information on ADHS/OCSHCN website or some other publicly available electronic resource for review by all of the agencies.

Objective 1.4. Define and monitor needs assessment activities to guide the overall committee functions.

Activity 1.4.1. Review and make recommendations on proposed needs assessment activities.

Activity 1.4.2. Aggregate current or within the past two years all studies being conducted in Arizona on the needs of c/yshcn.

Activity 1.4.3. Assist in the design, implementation and analysis of all needs assessments conducted under this grant.

Objective 1.5. Facilitate partnerships and joint application of funding to support the integration activities.

Activity 1.5.1. Members will provide Quarterly Reports of grant activities, status, and perceived obstacles to task completion.

Activity 1.5.2. Post activities and reports on the ADHS/OCSHCN web site.

Activity 1.5.3. Develop a List Serve to facilitate communication among all of the members.

Objective 1.6. Work in partnership with communities and other state agencies to implement coordinated enrollment and/or eligibility criteria.

Activity 1.6.1. Reports on the Universal Eligibility Application process will be reviewed by the Integration Task Force for a potential interface with the Task Force or to generate new action items for the subcommittees.

Objective 1.7. Work in partnership with communities and other state agencies to implement shared data and information systems.

Activity 1.7.1. Survey the partners as to the type of data collected, mechanism of storage (language, database, format).

Activity 1.7.2. Investigate the feasibility of adding data from shared members to the ADHS data warehouse.

Objective 1.8. Oversee the development and monitoring of the performance of six additional subcommittees: Education and Training Committee, Parent-Led Community Action Council, Youth Advisory Council, Cultural Competency Team, Interagency Community Development team, Quality Improvement Team, and Children's Rehabilitative Services Administrative and Clinical Team.

Activity 1.8.1. Teams will provide Quarterly Reports of activities status and perceived obstacles to task completion.

Goal 2. The Education and Training Committee will provide statewide coordination of the educational activities provided to professionals, agencies, as well as the c/yshcn and their families to reduce duplication and conflicting information.

Objective 2.1. Utilize needs assessment data to design and implement training programs for health care professionals, agency and service organization staff, and c/yshcn and their families.

Activity 2.1.1. Survey parent-leaders, youth, community teams, independent health care providers about computer skill level, comfort with e-learning, and potential content areas within the area of c/yshcn.

Objective 2.2. Develop a mechanism to collaborate and exchange training materials with other agencies/groups to reduce duplication and maintain consistency in the message(s) and to have youth and family members review training materials for appropriateness.

Activity 2.2.1. Work collaboratively with the Health and Ready to Work National Center to integrate national information and materials for youth, families, and providers in support of their successful transition to adulthood.

Activity 2.2.2. Work collaboratively with Southwest Human Development to integrate training about and for c/yshcn and their families into the planned trainings for behavioral health providers throughout the state.

Activity 2.2.3. Work collaboratively with the A. T. Still University of Health Sciences, Arizona School of Dentistry & Oral Health to develop and implement training of dental professionals to work with c/yshcn.

Activity 2.2.3.1. Raising Special Kids will add dental students to go through their existing training on parent-to-parent support, resources for c/yshcn, and send the dental students with Pediatric Residents on a home visit to a c/yshcn.

Activity 2.2.3.2. ADHS/OCSHCN will work with the Arizona School of Dentistry & Oral Health to develop a semester long curriculum on c/yshcn provided by youth and family members.

Activity 2.2.4. Work collaboratively with Burris (Duke) Duncan, MD to provide training to pediatric residents at the University of Arizona Medical School.

Activity 2.2.5. Work collaboratively with the state agencies involved in the Statewide Integration of Community-Based Services to develop and implement training of management and staff on the community development model.

Activity 2.2.6. Work collaboratively with NAU/IHD to:

Activity 2.2.6.1. Develop and implement training on consumer-to-consumer interviewing for quality improvement.

Activity 2.2.6.2. Provide training on the multidisciplinary treatment approach to a variety of health care professionals and educators.

Activity 2.2.7. Work collaboratively with Anu Partap, MD to provide a training module for primary care physicians on how to utilize Quality Improvement techniques in their practices.

Activity 2.2.8. Participate in the Fall 2005 conference being conducted by the Arizona Department of Education on Transition Issues for Youth in Arizona by providing travel and expenses for Patti Hackett, MEd, Co-Director for Healthy and Ready to Work National Center, in providing a national perspective on transition issues facing yshcn.

Objective 2.3. Develop e-learning curriculum and utilize e-learning management system to track learning activities.

Activity 2.3.1. Modules presently available through the Parent-Youth Leadership Institute will be: Breaking the Diagnosis, Parent-Physician Communication, Medical Home, and Youth Transition Issues.

Objective 2.4. Develop a train-the-trainer module to develop additional capacity for training utilizing the Parent Youth Leadership Institute materials.

Objective 2.5. Identify opportunities for youth and families to present the Arizona Experience with c/yshcn at local and national conferences.

Goal 3. The Parent-Led Community Action Council will be formed to create an oversight committee for all community development projects throughout the state and facilitate the cross training and mentoring by parents of other parents.

Objective 3.1. The ADHS/OCSHCN community teams will identify at a minimum one parent and one professional from each community to provide oversight and feedback regarding community-based activities.

Activity 3.1. Team members will meet four times a year to review local activities, and make recommendations for change through the use of a formal reporting mechanism to the Statewide Integrated Task Force.

Goal 4. A Youth Advisory Council will be formed to integrate the youth perspective into all activities of this grant.

Objective 4.1. Prepare youth and adolescents; families; medical home/pediatric and adult health care providers; the educational system; and the other components of the service delivery system that may affect individual adolescents and their families; for transition.

Activity 4.1.2. Develop brochures for parents, medical professionals, and community groups on transition issues from the perspective of the youth.

Activity 4.1.3. Conduct face-to-face interviews with youth in the community to develop Community Adolescent Health Profiles.

Objective 4.2. Provide youth with information and resources on long-term health, access to independent living, and personal assistance services.

Activity 4.2.1. In conjunction with the Arizona Transition Leadership Team, act as a clearinghouse of information, and provide a directory of services and resources for youth

of transition age, including how to access, eligibility requirements, etc on the ADHS/OCSHCN website by July 2005.

Activity 4.2.2. Obtain data on school attendance, dropouts, graduation rates from schools by youth with disabilities throughout Arizona and post on the ADHS/OCSHCN website by January 2006.

Objective 4.3. Develop a referral network and other information on how to access pre-vocational counseling and training by June 2005.

Activity 4.3.1. Survey the membership of the Arizona Transition Leadership Team about training resources, locations, contacts, entrance requirements, costs and potential funding/scholarship alternative by January 2006.

Activity 4.3.2. Provide a list of pre-vocational counseling and training on the ADHS/OCSHCN website by March 2006.

Objective 4.4. Provide capacity building and training of the health care system

Activity 4.4.1. Develop a List Serve of yshcn in Arizona in conjunction with the ADHS/OCSHCN website by June 2006.

Activity 4.4.2. Provide the Parent Youth Leadership Training modules to youth in local communities so they can participate in their local community development teams.

Objective 4.5. Develop youth as self-advocates.

Activity 4.5.1. In conjunction with the Arizona Transition Leadership Team, provide opportunities to educate youth and families about opportunities and services.

Activity 4.5.2. Conduct focus groups with youth throughout the state in a variety of settings, including educational and health care settings to identify the most significant areas where youth need information to assist in becoming self-advocates.

Activity 4.5.3. Develop fact sheets on issues related to transition that can be downloaded from the ADHS/OCSHCN website by January 2005.

Activity 4.5.4. Develop mechanisms to capture baseline and on-going data on opportunities for youth to self-advocate and the outcome of these self-advocacy activities.

Activity 4.5.5. Integrate the community development work of the OCSHCN into the Arizona Transition Leadership Team.

Activity 4.5.6. Work cooperatively with ADHS/BHS to identify youth with behavioral health problems that can become part of the youth teams.

Objective 4.6. Develop a compensated and diverse Youth Advisory Council.

Activity 4.6.1. Identify potential youth who have participated in the Youth Parent Leadership Training to participate as a development committee by August 2005.

Activity 4.6.2. Recruit youth members from the existing community teams throughout the state by August 2005.

Activity 4.6.3. Provide Youth and Parent leadership training to members who have not completed by September 2005.

Activity 4.6.4. The Youth Advisory Committee will develop their mission, vision, and strategic goals by January 2006.

Objective 4.7. Work collaboratively with the Governor's Council on Developmental Disability as they develop their statewide network of consumers, self-advocates, and families.

Goal 5. Develop a Cultural Competency Team to support all the activities of the Statewide Integration Team

Objective 5.1. Support participation of traditionally under-represented families in decision-making, educational and technical assistance activities.

Activity 5.1.1. Identify unmet needs of c/yshcn and their families in Native American communities through needs assessment of tribal members.

Activity 5.1.2. Identify cultural-specific resources for families of other cultures and ethnicity and provide resources and educational materials about services and support for c/yshcn and their families.

Activity 5.1.3. Identify individuals within state and community based organizations to participate in the design of an integrated system of care for c/yshcn that is representative of the various racial, ethnic, and cultural diversity within the state of Arizona.

Activity 5.1.4. Evaluate all training materials and written documentation for language-specificity by population and cultural appropriateness.

Activity 5.1.5. Develop a list of language proficient staff and affiliated families within agencies and community-based organizations that can be utilized for translation services.

Activity 5.1.6. Promote multilingualism as an educational opportunity for staff, youth, and parents.

Activity 5.1.7. Provide written documentation regarding the interplay of cultural beliefs with health care beliefs, the value of community support for family with a chronically ill child, the integration of cultural values with acceptance of children with special health care needs.

Objective 5.2. Develop Youth/Parent Leadership training materials in appropriate language and other media for racial/ethnically diverse and disabled populations.

Objective 5.3. Recruit additional community team members for the community development teams that are representative of the economic, racial, and ethnic diversity of the communities they serve.

Objective 5.4. Develop at least two new community teams comprised primarily of Native Americans and Hispanic community members by January 2006.

Goal 6. Develop an Interagency Community Development Team to promote family-centered care through partnerships between families with c/yshcn and health professionals and policy makers to improve the quality of life of c/yshcn as well as that of the health care delivery system.

Objective 6.1. Conduct a needs assessment of each agency participating in the Community Development Initiative and identify needs by agency for training of staff; identification, training, and mentoring of parent leaders; and implementation plans.

Objective 6.2. Expand the community development model to other state agencies through the Community Development Initiative

Activity 6.2.1. Provide training for yshcn and their parents participating in the Statewide Integration of Community-Based Services through the Youth/Parent Leadership Development Institute.

Activity 6.2.2. Provide training on how to work with community development teams to other Arizona State, County, and local agencies.

Activity 6.2.3. Identify parents from existing parent-led community teams that can provide mentoring to other parents.

Activity 6.2.4. Utilize Partners in Policy Making, Raising Special Kids, Pilot Parents, AzEIP parents, and ADHC/OCSHCN Community teams as a pool of potential youth and parents.

Objective 6.3. Obtain operating manuals, policies and procedures from partner agencies.

Objective 6.4. Initiate activities to develop a community team within one of the Native American communities.

Objective 6.5. Develop linguistically and culturally appropriate materials for the teams.

Objective 6.6. Consult with Mark Holman, PhD regarding implementation of community development teams throughout the state.

Goal 7. Develop a Quality Improvement Team to oversee all of the data collection procedures, analysis, and reporting to the Statewide Integration Task Force.

Objective 7.1. Evaluate all data collection activities for appropriateness of instrument selection, data analysis plan and implementation, and interpretation of the results.

Objective 7.2. Evaluate the effectiveness of the youth and parent involvement activities.

Activity 7.2.1 Survey parents in existing state agencies where there is no parent involvement to determine perceived needs of parents.

Activity 7.2.2. Survey agency leadership regarding expectations of parent involvement.

Activity 7.2.3. Develop and utilize measures of youth and family satisfaction.

Objective 7.3. Establish specific performance measures for the following types of data.

Activity 7.3.1. System structure. Establish and measure structural aspects of system changes. Measures will include the number of professional staff, community agency staff, youth, and parents trained.

Activity 7.3.2. System practice/process. Measure fidelity to performance expectations.

Activity 7.3.3. Identify Barriers.

Activity 7.3.4. Collect data to assess clinical and systems outcomes.

Objective 7.4. Data will be reviewed, additional studies proposed, and changes made to processes by the committee.

Objective 7.5. In collaboration with NAU/IHD train youth and parents on consumer-to-consumer interviewing to identify quality issues throughout the system.

Activity 7.5.1. Identify team members for training by August 2005.

Activity 7.5.2. Provide training by November 2006.

Activity 7.5.3. Begin presenting findings to the Quality Improvement Committee to assist in the identification of problems that needs to be modified.

Goal 8. Develop a Specialty Services Team that will examine how to facilitate ease of use of specialty services and how to better link primary and specialty care for c/yshcn.

Objective 8.1. Provide the Flagstaff CRS Clinic with the capability to provide real-time examinations at rural/Native American locations and store that information for retrieval by a specialist at a later time via the telemedicine system.

Goal 9. Provide well-documented coordination strategies that link medical homes to other community-based services and other health-related needs.

Objective 9.1. Collect needs assessment data from the physician membership of the Arizona Chapter of the AAP regarding attitudes toward, and readiness to work within a Medical Home utilizing both a survey and selected focus groups.

Activity 9.1.1. Design needs assessment for AAP by August 2005.

Activity 9.1.2. Purchase web-based software for surveys and create web-based version of survey by July 2005.

Activity 9.1.3. Design database and analytic plan by August 2005.

Activity 9.1.4. Obtain e-mail addresses for AzAAP membership by August 2005.

Activity 9.1.5. Field-test survey and data collection mechanism by September 2005.

Activity 9.1.6. Conduct survey through December 2005.

Activity 9.1.7. Conduct focus groups through February 2006.

Objective 9.2. Collect needs assessment through the use of focus groups conducted with the OCSHCN Community Development teams, the OCSHCN contracted service providers, and other designated key informants about the strengths and weakness of screening, referral, and care coordination activities in their communities.

Objective 9.3. Select two Medical Home/physician offices locations by January 2006.

Activity 9.3.1. In conjunction with the Quality Improvement Team, the Youth Action Council, and the Parent-led Community Development Council, OCSHCN staff will make recommendations to the Integrated Services Task Force on the selection of the Medical Home locations.

The criteria for selection will be:

- a. Medical Home sites must agree to have a full-time screener at their location who will provide screening services to all children and youth within the clinic, provide the results of the screening to the physicians, ensure that these results become part of the medical record and will be shared with the parent/guardian and child/youth, as appropriate;
- b. Medical Home sites must agree to participate through the use of multiple communication devices, including web-based electronic communication regarding the children and youth who are identified with positive screens;
- c. Medical Home sites will follow accepted practices for Release of Information Forms and HIPAA compliance;
- d. Medical practices must accept all forms of insurance coverage, including AHCCCS/Medicaid;
- e. Medical practices cannot have a current screener or care coordinator participating with their practice;
- f. Medical practices must be open to all children and youth; and
- g. Medical practices must provide primary care services to the full age range of children and adolescents, not just specialty care services.

Objective 9.4. Select two school-based clinics locations by June 2005.

Activity 9.4.1. In conjunction with the Quality Improvement Team, the Youth Action Council, the Parent-led Community Development Council, and OCSHCN staff will make recommendations to the Integrated Services Task Force on the selection of the school-based clinics locations.

The criteria for selection will be:

- a. School-based clinics must have clinical services available at least three times a week with an on-site clinical staff person from the school available for the students.
- b. School-based clinics must notify parents of the availability of a screener and the potential of referrals for other services.
- c. School-based clinics will comply with appropriate Release of Information documentation required by standards of practice and governing practices of the school district.

Objective 9.5. Provide a Medical Home Screener at each of the designated Medical Home sites that will provide developmental, mental health, oral, and transition screening services to all children and adolescents who receive clinical care services at the Medical Home site by June 2005.

Activity 9.5.1 Collect needs assessments data from a survey of private physicians regarding their knowledge of, and use of screening and intervention of children 0 – 5

years of age, in conjunction with Anu Partap, MD, pediatrician working with MedPro, a large multi-specialty physician organization affiliated with Maricopa Medical Center in Phoenix, Arizona.

Activity 9.5.2. In consultation with the AzAAP, Quality Improvement Team, the Youth Advisory Council, and the Parent-led Community Development Council, select instruments that will be simple to use and score and provide for the ability to compare with other state and national prevalence and outcome data.

Activity 9.5.3. Involve clinicians from the designated Medical Homes, parents and yshcn from the Youth Council and the Parent-led Community Development Council, and OCSHCN staff in the recruitment, hiring, and training of community-based screeners for each of the Medical Home sites by July 2005.

Activity 9.5.4. Purchase screening instruments.

Activity 9.5.5. Train all clinical staff on screening tools, scoring, documentation, and referral procedures.

Objective 9.6 Conduct transition screening of all youth over the age of 12 and their parents in the four clinical sites to determine youth and parent's knowledge level and needs regarding transition issues.

Activity 9.6.1 Develop screening instrument in conjunction with the Integration Task Force members, community partners, youth, parents, and the National Center for Healthy and Ready to Work by January 2006.

Activity 9.6.2. Develop an Adolescent Health Profile as part of the community needs assessment that provides data on 21 Critical Health Objectives for local communities.

Objective 9.7. The Medical Home Screener will refer all children and youth who screen positive on any of the screening instruments to the OCSHCN Care Coordinator by June 2006.

Activity 9.7.1. Determine procedures within each screening site to identify new patients and administer, document, and discuss the results with the attending physician or other senior medical staff person.

Activity 9.7.2. Determine procedures within each Medical Home/screening site to inform the parents of the screening process, obtain informed consents to screen.

Activity 9.7.3. Determine procedures for referral of positive screening result to the OCSHCN Care Coordinator(s) and how to inform parents of referral.

Objective 9.8 Define the role and function of the OCSHCN Care Coordinator(s) utilizing National Medical Home Project resources.

Activity 9.8.1. Create job description by October 2005.

Activity 9.8.2. Hire and train OCSHCN Care Coordinator(s) by December 2005.

Activity 9.8.3. Develop quality improvement monitors to ensure satisfactory compliance with expectations by January 2006.

Objective 9.10. Review and select appropriate technology that will facilitate web-based, multi-disciplinary communication between all members of a c/yshcn's treatment team and family.

Objective 9.11. Youth and Parent Advisory Councils will participate in the development and implementation of all phases of the Coordination Care Study.

Objective 9.12. Utilize models from the National Medical Home project to identify keys to success and barriers to implementation.

Objective 9.13. Develop a social marketing campaign to promote the development of and use by c/yshcn.

Activity 9.13.1. Develop text for public service/commercial announcements about medical home: what it is; how to talk to your physician about being a medical home; and the advantages of having a medical home.

Activity 9.13.1.1. Target separate audiences, parents, physicians, and communities.

Activity 9.13.1.2. Utilize parents and youth to develop a version for c/yshcn and their families.

Activity 9.13.1.3. Utilize pediatricians to talk about how to implement a medical home for physicians and other practitioners.

Activity 9.13.1.4. Distribute text about medical home as well as the names of youth and families for potential interviews to various media outlets throughout the state.

Activity 9.13.2. Develop video and CD of what comprises a medical home in conjunction with Northern Arizona University and AzAAP for distribution to pediatrician's offices and to family members of c/yshcn.

Objective 9.14. Support data capacity for integrating screening results across relevant programs.

Objective 9.15. Expand the scope of the screening processes conducted in private physician offices and clinics.

Goal 10. Devise a plan for sustainability of the parent-led teams working with other agencies.

Objective 10.1. Investigate shared funding between the agencies of community teams and their activities.

Objective 10.2. Encourage all members of the Integrated Task Force to include funding of the community development teams in any grant proposals or Requests for Proposal.

Objective 10.3. Share the currently developed Community Development Teams Sustainability Plans with other agencies.

Goal 11. Produce a position paper that will integrate information and provide specific recommendations on how to improve the system of community-based care for c/yshcn to the Governor.

Objective 11.1. Work collaboratively with an external financial consulting firm to analyze data from the activities of the Integration Task Force and the Coordination of Care Study. These analyses will become part of the position paper sent to the Governor.

Activity 11.1.1. Submit the position paper to the Integration Task Force for discussion, review, and comment by June 2008.

Activity 11.1.2. Submit position paper to the governor by September 2008.

Activity 11.1.2. Post position paper on the ADHS/OCSHCN website.

Objective 11.2. Evaluate the impact of changing payer coverage for screening and care coordination.

Objective 11.3. Work collaboratively with the National Center on Health Care Financing.

Goal 12. Evaluate the insurance coverage of c/yshcn.

Objective 12.1. Assess the adequacy of coverage for c/yshcn.

Objective 12.2. Evaluate how c/yshcn are identified within private insurance companies and how services are coordinated.

Objective 12.3. Work in partnership with communities and other state agencies to identify and implement coordinated financing of services, as appropriate.

Objective 12.4. Evaluate the number of c/yshcn who are uninsured or do not have continuous insurance and make recommendations.

Activity 12.4.1. Survey families from partner agencies about insurance availability, cost, and eligibility.

IV. Work plan

Activities or steps with time line and assigned staff

#	Goal	Objective	Activity	Staff	Other Expenses	Year 1		Year 2		Year 3	
						1-6	7-12	1-6	7-12	1-6	7-12
1	Create a statewide forum	Statewide Integration Task Force	Monthly meeting for first 6 months, then quarterly	CE, JC, JW, CL, BH, TL, MU Youth and Parents *	Travel and hourly rate for youth and parents *						
			Circulate proposal	JC							
			Convene follow-up meeting	JC							
		Develop action plan		CE, JC, JW, CL, BH, TL, MU Youth and Parents *	Travel and hourly rate for youth and parents *						
		Identify key activities of partners	Obtain list and post on OCSHCN website	JC, TL							
		Define and monitor needs assessment activities		CE, JC, JW, CL, BH, TL Youth and Parents *	Travel and hourly rate for youth and parents *						
		Facilitate partnerships	Quarterly reports of members	JC, TL							
			Post activities on OCSHCN website								
			Develop a List Serve for task force members								
		Coordinated eligibility and enrollment	Coordinate with Universal Application Task Force	CE							
		Evaluate shared data systems		JC							
		Evaluate number of uninsured c/yshcn		JC							
		Oversee subcommittees		JC							
2	Create an Education and Training Committee	Schedule monthly meetings		JC, JW, TL Youth and Parents *	Travel and hourly rate for youth and parents *						
		Conduct needs assessment of training needs of agencies, youth, and		JC, TL, VC	Scanning equipment						

		parents									
		Collaborate with other agencies on training activities	Integrate information from Health and Ready to Work Work with Southwest Human Development to integrate trainings and materials Professionals and dentists.	JW, TL							
			Work with Raising Special Kids to provide training on providing services to c/yshcn to medical	JW, TL Raising Special Kids	E-Learning						
			Work with NAU/IHD to implement a consumer-to-consumer interviewing process for quality improvement	JW, TL, Dr. Uno							
			Work with NAU/IHD to provide interdisciplinary training to health care professionals.	JW, TL, Dr. Uno							
			Work with Dr. Partap to train physicians on quality improvement processes to use in their offices.	JC, TL, Dr. Partap							
			Participate in Department of Education Conference on Transition Issues	Patti Hackett	Travel Per Diem						
3	Create a Parent-led Community Action Council			JC, JW, TL Youth and Parents *	Travel and hourly rate for youth and parents *						
4	Create a Youth Advisory Council			JC, JW, TL Youth *	Travel and hourly rate for youth *						
5	Create a Cultural Competency Team	Support participation of under-represented families	Assess needs of tribal members	JC, TL, Michael Allison, IHS, Youth and Parents *	Travel and hourly rate for youth and parents *						
			Identify culturally-specific resources								
			Identify potential								

			community team members from different races and cultures									
			Evaluate training materials									
			Identify multilingual staff in all agencies/ communities									
			Promote multilingualism									
			Provide educational materials on impact of culture on health beliefs		Production, Distribution, Cultural Competency Training							
		Develop training materials in other languages		MA, Bilingual Parents, Youth	Community Team Materials/ Translation							
		Recruit youth and family from under-represented members of the communities										
		Assist in the development new community teams in Native American and Hispanic communities			New Community Teams							
6	Create a Interagency Community Development Team	Conduct needs assessment of agencies participating the Community Development Initiative		CE, BH, MU, TL Youth and Parents *	Travel and hourly rate for youth and parents *							
		Expand Community Development model to other state agencies	Provide training to yshcn and parents through Youth/Parent Leadership Institute.		Train the Trainer							
			Provide training to agencies on how to work with Community Development teams and families		Community Development Specialist							
			Provide parent-to-parent mentoring									
			Utilize grassroots organizations to develop									

			youth and families to work with agencies								
		Obtain policies and procedures from agencies involved in Initiative		JW, BH, TL, MU							
		Initiate activities within one Native Community to foster team development		BH, JW, MU, TL,	New Community Team						
		Consult with Mark Homan		BH, JW, MU, TL							
7	Create a Quality Improvement Team	Evaluate all data collection activities		JC, JW, TL Youth and Parents *	Travel and hourly rate for youth and parents *						
		Evaluate effectiveness of youth and parent involvement	Survey parent and youth in agencies	JC, VC	Data Collection, Scantron Hardware and Software						
			Survey agency leadership about expectations of youth and parent involvement	JC, VC	Develop, Analysis, Distribution of Surveys						
			Measure youth and family satisfaction	JC, VC							
		Establish specific performance measures		QI, CD	Travel and hourly rate for youth and parents *						
		Review data quarterly		QI	Data Collection, Analysis						
		Collaborate with NAU/IHD to train youth and parents on consumer-to-consumer interviewing	Identify team members to train	JW, TL, MU, NAU							
			Train team members	NAU	Travel and hourly rate for youth and parents *						
			Begin gathering data and present results to QI Committee	NAU, QI							
8	Develop Specialty Services Team	Provide Flagstaff CRS Clinic with telemedicine equipment			Store and Forward Tele-Medicine Equipment						

9	Provide well-documented coordination strategies to link medical home to community-based services	Collect needs assessment data	Design and implement survey of AzAAP membership	JC, TL, VC	Scanning equipment						
			Design and implement focus groups with selected AzAAP membership	JC, VC, AzAAP	Data Collection						
			Design and implement focus groups to be conducted with Community Development Teams and other key informants on strengths and weaknesses of screening, referral, and care coordination	JC, VC, MU, TL	Data Collection						
		Select two medical home sites	Solicit recommendations from key members of the pediatric and social service delivery system	AzAAP	Travel and hourly rate for youth and parents *						
			Apply selection criteria	OCSHCN							
		Select two school-based clinics	Apply selection criteria	OCSHCN							
		Provide medical home screener at each site	Survey private physicians about knowledge regarding screening	JC, VC, AP							
			Select screens and purchase	QI, CD	Screening tool						
			Involve committee members in hiring process	4 FTE Screeners	Travel and hourly rate for youth and parents *						
			Train all clinical staff on screening procedures	TL, JC	3 Screeners						
			Conduct transition screens on all youth at all clinical sites	Develop screening instrument for adolescents	3 Screeners						
				Develop Adolescent health Profile	Youth						
		Refer positive screens to	Develop policies and	1 FTE Screener,	Screeners						

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		Care Coordinator	procedures	Care Coordinator							
		Provide care coordination for children and youth needing services following a positive screen	Hire Care Coordinator	1 .5 FTE Care Coordinator	Care Coordinator						
			Develop quality monitors to ensure satisfactory compliance with expectations		Travel and hourly rate for youth and parents *						
		Employ web-based electronic communication		TL	Care Coordination Web Software Technology						
		Youth and parents will advise all aspects of the Care Coordination Study		TL	Travel and hourly rate for youth and parents *						
		Utilize models from the National Medical Home Project									
		Develop Social Marketing campaign to increase knowledge of medical home in the community	Develop text, interview subjects and present to media	JC, TL	Social Marketing						
			Develop a video, in conjunction with NAU/IHD, where a YSHCN and a parent describe a medical home	TL	NAU Video Project						
		Support data integration across relevant programs			Data Collection						
		Expand scope of screening in private physician's office			3 Screeners						
10	Develop a Sustainability Plan	Investigate shared funding of Community Development Teams by multiple agencies		CE, JC, TL,	Travel and hourly rate for youth and parents *						
		Include Community Development activity in proposal/grants submitted by Integrated Task Force		MU, BH	Travel and hourly rate for youth and parents *						

		members									
		Share Community Development team Sustainability Plans		MU, BH	Travel and hourly rate for youth and parents *						
11	Produce position paper	Work with external consulting firm to analyze data and write position paper		CE, JC, TL Consultant	Position Paper Costs, External Analysis, Professional Writing and Publishing Services						
		Evaluate the impact of changing payer coverage for screening and care coordination									
		Work collaboratively with the National Center on Health Care Financing									
11	Evaluate insurance coverage for c/yshcn	Access adequacy of coverage		CE, JC, TL	External Analysis						
		Evaluate how c/yshcn are identified and case managed by private payers		TL							
		Work with communities and agencies to coordinate financing		JC, BH	Travel and hourly rate for youth and parents *						

* ADA Support will be provided through a contract with Pilot Parents for those youth and parents requiring services.

JC: Jacquilyn Kay Cox, PhD, Principal Investigator

CE, Cathryn Echeverria, ADHS/OCSHCN Office Chief

JW, Judith Walker, ADHS/OCSHCN Section Manager, Education and Advocacy,

BH, Barbara Hess, ADHS/OCSHCN Section Manager, System of Care

TL, Todd Lewis, Program Manager

VC, Vatsal Chilkani, Research Chief, ADHS/OCSHCN

MU, Marta Urbina, Community Development Program Manager, ADHS/OCSHCN

AP, Anu Partap MD, MPH, Director, Arizona Center for Community Pediatrics

V. Resolution of Challenges

Potential Barriers to Implementation and Methodology for Addressing

The barriers to building a medical home include limited time and personnel resources in the primary care office, limited reimbursement for care coordination activities, lack of understanding of the MCHB Title V program and the six core performance measures, lack of a uniform medical home definition and message, and transition service gaps. This proposal addresses these three issues in five separate ways:

- To address the limited time and personnel resources in the primary care office, it is proposed that for the duration of this study period a bilingual screener will be placed in each of the designated clinical sites, paid for out of the grant dollars. Additionally a Care Coordinator, outside of the practice, will facilitate referrals to agencies, providers, and support groups.
- To address the limited reimbursement for care coordination we will evaluate the hypothesis that when there is a designated individual to provide linkages to public programs, facilitate documentation of services (i.e., screening and care coordination), that fewer dollars will be expended on unnecessary health care services (e.g., emergency room visits), less frequent, shorter duration hospital stays, and greater satisfaction by both the health care providers and the family.
- To address the lack of a uniform medical home definition and message we are proposing a social marketing campaign designed to create a consistent message and reinforce that with various public service announcements and the production of a short video where c/yshcn and their families talk about what is a medical home.
- To address the lack of understanding of the MCHB Title V program and the six core performance measures, we will include this information with all discussion about a medical home through the social marketing activities.
- To address the transition gaps, we intend to work extensively with youth, communities, and agencies to identify and quantify these gaps and develop inter-agencies activities to address the gaps.

An area of strength in Arizona is the newly developed task forces to address the Universal Application whereby multiple and redundant applications for services are being streamlined into a single unified process, the Community Development Initiative which is expanding upon the work of ADHS/OCSHCN Community Teams and family involvement to other state agencies, and finally the initiation of the Arizona Leadership Transition Team is developing action items across all state agencies serving the needs of children and youth to facilitate an improved process for transitioning children and youth through various phases of education, health care and financial services. These committees form the foundation of integrating services for children and youth across multiple service groups and as these committees mature there will no doubt be opportunities to change and modify the system in new and creative ways. It is the intent of this grant to address integration further through the areas of education and training, cultural competency, and enhanced participation of youth and families in the design and evaluation of systems.

The issue of medical home is not whether people believe the concept is a good one; the issue is who will pay for this much needed coordination. Recent data analysis from the current Medical Home grantee in Arizona showed that physicians who see large numbers of CSHCN generate significantly less revenue than do physicians who see predominately well children (personal communication, Karen Burstein, 2004). The problem is that lack of reimbursement for the extra time that these patients require. It is the intent of this grant to show with a large number of children in a variety of different clinical settings, the provision of a screener and an external Care Coordinator will facilitate the more timely receipt of services and a better health outcome. These data can then be used to argue for the addition of a revenue code for both screening and care coordination.

VI. Evaluation and Technical Support Capacity

The Arizona Department of Health Services (ADHS), Office for Children with Special Health Care Needs (OCSHCN), under the direction of Jacquilyn Kay Cox, PhD, Section Manager of Data, Planning & Evaluation and Vatsal Chilkani, Research Chief, will oversee the evaluation.

Goal 1: Create a statewide forum					
Structural Measures	Data Source	Process Measures	Data Source	Outcome Measures	Data Source
Development and maintenance of Task Force and all subcommittees	Task Force agenda and minutes				
# Members in attendance # Agencies represented # Parent and youth represented Geographic representation Cultural and ethnic representation	Task Force attendance roster by name, affiliation, and address			Satisfaction rates of participating members	
Development of action plan	Task Force minutes	Thoroughness and follow-up of action plan	Task Force Action Plan	Monitor timelines of action plan	PERT charts
Development of monitoring process for needs assessment data	Task Force Action Plan and minutes	Identify barriers to completion of timelines	Task Force Action Plan		
Create review system of grants, RFPs for shared participation	Task Force minutes	# RFPs/grant proposals reviewed	Task Force minutes	# Joint RFP/grant proposal submissions	
Share Universal Application Reports	Task Force minutes	# c/yshcn who completed Universal Application process	Universal Application Reports	Satisfaction rates from yshcn and their parents	Satisfaction survey annually
Status report	Quarterly	Barrier analysis	Quarterly reports	Peer review of process	Survey
Goal 2. Education and Training Committee (ET)					
Identify membership		Needs assessment	Surveys		
Attendance		Computer skill survey	Surveys		
# parent and youth represented geographic representation cultural and ethnic representation	Task Force attendance roster by name, affiliation, and address	Development of web site for combined cross agency training calendar	ET Quarterly report	Peer review of process	Survey
Action Plan		# Training modules on web	ET Quarterly report	Completion rates of web training	e-learning management
Coordination plan for integrating educational activities across agencies	ET Action Plan	# Agencies and staff utilizing e-learning management system	e-learning management reports	Satisfaction of people utilizing e-learning management system	Satisfaction scores of people registered on e-

					learning site
Status report	Quarterly	# Trainings conducted jointly by one or more member organizations	ET Quarterly report	Satisfaction with all trainings provided	Satisfaction surveys
		# Trainings to pediatric residents, dental students, nurses and other health care professional	ET Quarterly report	Recommendations for change and/or suggestions for new trainings	Satisfaction surveys
		# Primary care physicians trained on QI	ET Quarterly report	# Physicians implementing QI processes in practices	Telephone survey
		# Graduates of train-the-trainer	ET Quarterly report	Satisfaction with implementation of QI processes	Webmaster Reports
		# Trainings provided by graduates of train-the-trainer	ET Quarterly report	# Web hits on training calendar	
		# New parent and youth leaders enrolled in Leadership Institute courses and their satisfaction with training			
		# Agency staff trained by parent and youth leaders and their satisfaction with the training			
		# Parents and youth working with other agencies			
Goal 3: Parent Community Action Council					
Define membership	PCAC agenda and minutes		PCAC	# Recommendations made to the Integrated Task Force	ITF agenda and minutes
Develop action plan	Plan document	Review parent-led activities	PCAC minutes	Satisfaction of parent participants	Survey
Develop review process	Review document	Community Needs Assessment	Report	Peer review of process	Survey
Develop reporting process	Report form				
# Members in attendance # Parent and youth represented Geographic representation Cultural and ethnic representation	Roster				
Status report	Quarterly Report	Barrier Analysis	Quarterly Report		
Goal 4.: Youth Advisory Council					
Define membership	Quarterly Report	# Adolescent Health Profiles conducted	Adolescent Health Questionnaire	Analytic report of Adolescent Health Profiles	Report
Define mission and goals	Quarterly Report	# Brochures developed	Quarterly	Impact on Arizona Transition	Survey

		# Brochures distributed	Report	Leadership Team	Interviews
# Attendees at meeting	Quarterly Report	Educational resources for youth developed	Availability # Web hits	Satisfaction of access to and use of educational resources	Survey of web users
	Quarterly Report	List Serve for Youth # Users of List Serve	Availability Web hits	Satisfaction users of list serve	Survey/ interview
Develop action plan	Quarterly Report	# Trainings for youth and families	Quarterly Report	Satisfaction with all trainings	Survey/ interview
Develop review process	Quarterly Report	# Youth training professionals	Quarterly Report	Impact of advocacy	Interviews with key stakeholders
Develop reporting process	Quarterly Report	# Youth serving as advocates	Quarterly Report	Peer to peer evaluations	Survey
	Quarterly Report	Barrier analysis	Quarterly Report		
Status report	Quarterly Report				
<u>Goal 5: Cultural Competency Team</u>					
Define membership	Quarterly Report	Needs assessment of Native American Community	Survey	Evaluate attitudes of communities toward state, federal, and tribal agencies prior to activity.	Consumer to consumer interviews
# Attendees at meeting Diversity of the members # Agencies involved with minority health participating with team	Quarterly Report	# Cultural resources identified # Materials translated # Web hits	Web availability	Conduct post-intervention survey of attitudes	Consumer to consumer interviews
Develop action plan	Quarterly Report	Assist in the development community development team in underserved Native American and Hispanic communities	Interview team members	Community survey of effectiveness of cultural competency team interventions	Interviews with key stakeholders
Develop review process	Quarterly Report	# Documents reviewed and modified for cultural and language appropriateness	Quarterly Report		
Develop reporting process	Quarterly Report				
Status report	Quarterly Report				
<u>Goal 6: Interagency Community Development Team</u>					
Define membership	Quarterly Report				
Develop reporting process	Quarterly Report				
<u>Goal 7: Quality Improvement Team</u>					
Define membership	Quarterly Report	Outline the critical processes in the coordination of car study and develop a monitoring system	Quarterly Report	Consumer-to-consumer interviews on quality of care issues conducted at the community level.	Interviews

# Attendees at meeting	Quarterly Report	Establish benchmarks for processes, timelines, and outcomes based on National standards	Quarterly Report	Survey of parents and youth in state agencies where there is no parent involvement to determine needs.	Survey
Develop action plan	Quarterly Report	Review data quarterly	Quarterly Report		
Develop review process	Quarterly Report	Evaluate data collection processes, type of data collected, analyses, and reporting systems for all aspects of the project	Quarterly Report		
Develop reporting process	Quarterly Report				
Goal 8: Specialty Service Team					
Define membership		Children's Rehabilitative Services (CRS) will define a process of communicating and sharing data with the Integrated Service Task Force.		Share survey data from CRS Clinic	Aggregate report
Develop reporting process	To be determined				
Goal 9: Link medical home to other services					
Select medical home/screening sites	Quarterly report to Integrated Service Task Force	Conduct survey of the membership of AzAAP about medical home	Survey	Measure functionality, quality of life pre and post addition of screener and care coordinator	Quality of Life Measures
Hire screeners and evaluate performance quarterly	Performance reports	Conduct survey of the membership of AzAAP about early and continuous screening	Survey	Evaluate quality of services delivered	Standardized satisfaction measure Consumer to consumer interviews
Hire Care Coordinator and evaluate performance quarterly	Performance reports	Conduct focus groups with physicians throughout the state around medical home	Focus groups	Effectiveness of screener	Chart audits of medical home/screening sites
		# Children screened; # Children positive on each of the screens; # Children referred to OCSHCN care coordinator; # Children referred for additional services by the OCSHCN care	Monthly reports from sites	Patient and Family Satisfaction	Chart audit of medical home/screening sites

		coordinator; # Children not eligible for services and the reasons for lack of eligibility; # Children with no insurance coverage for needed services # Children with no referral # Children with no necessary follow-up care			
		Time to obtain a referral from positive screen Time to access services Time to become eligible for services	Logs Monthly reports from sites	Appropriateness of the referral to the Care Coordinator	Chart audit
		Institute quality improvement monitors	Quality Improvement Committee Report		
		Patient/family complaints		Impact on clinical sites	Interviews with clinical staff
		Parent and youth involvement at medical home/screening sites	Interviews with community development, parent-led teams, and youth advisory council		
		Barrier analysis	Interviews with key staff, youth and parents		
<u>Goal 10: Community develop team sustainability</u>					
Define membership	Quarterly report	Survey agencies about ability to co-fund existing or new community development teams	Survey	Satisfaction of existing team members with the inclusion of other agencies	Survey
# Attendees at meeting	Quarterly report	Review new grants proposals from membership for integration with community team development.	Review Integrated Task Force Reports	# New members added to exiting teams	Quarterly Report
Develop action plan	Quarterly report			# New teams under development	Quarterly Report

Develop review process	Quarterly report				
Develop reporting process	Quarterly report				
Status report	Quarterly				
Goal 11: Position Paper					
Define work group and timeline	Report to Integration Task Force	Complete position paper	Paper	Response to position paper	Survey Integration Task Force Members and Governor
Goal 12: Evaluate insurance coverage for c/yshcn					
Develop survey internal to OCSHCN and review with Integrated Task Force	Survey	Survey of c/yshcn regarding insurance coverage	Survey	Include findings in Position Paper	

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VII. Organizational Information

A. Current Mission and Structure

The mission of the Arizona Department of Health Services/Office for Children with Special Health Care Needs is to continuously improve comprehensive systems of care which enhance the health, future and quality of life for you and children with special health care needs, their families and the communities in which they live. The Office for Children with Special Health Care Needs (OCSHCN) is organized around five functional areas that were defined as part of a strategic planning process: Data, Planning and Evaluation, Systems of Care Development, Program and Quality Management, Education and Advocacy, and Finance and Business.

B. Scope Of Current Activities

Direct Services - The Office for Children with Special Health Care Needs (OCSHCN) contracts for a wide array of diagnostic, treatment, referral, and education services through the Children's Rehabilitative Services Program (CRS), the Arizona Early Intervention Program (AzEIP), and the Sickle Cell Anemia Program.

Community Development - Consultation and technical assistance are provided to children/youth with special health care needs, their families, and local leaders so that they can identify issues, set priorities, develop and implement plans, and evaluate efforts to make services and community life better for the target population.

Systems Development - OCSHCN facilitates efforts by families, state and local agencies, community-based organizations, and policy makers to make the system of care more accessible, comprehensive, and coordinated, and to improve the quality of care provided. Programs involved in systems development are Asthma, CRS, Medical Home, Tele-Health/Tele-Medicine, and Traumatic Brain Injury.

Education - Technical education on clinical practice, public health methods, and systems of care is provided to lay and professional groups. Additionally, OCSHCN works to educate the community about the place of c/yshcn in society.

Advocacy - OCSHCN advocates for the inclusion of c/yshcn and their families in the development and implementation of the policies and programs that affect them.

Data - Using a variety of methods, data is collected, analyzed and disseminated about the incidence and prevalence of various diseases and conditions, community needs and resources, and knowledge, attitudes and beliefs. The data is used for policy and program planning and evaluation.

Quality Improvement - Program outcomes, both clinical and community, are routinely assessed to determine areas performing well and those that need improvement. Guidelines are used to achieve consistent results throughout the state.

Public / Private Partnerships - In order to maximize efforts, OCSHCN strives to closely collaborate with families, providers, community-based organizations, and policy makers. These partners, that reflect Arizona's diverse population, contribute to the development and implementation of materials, programs and policies.

C. Organizational Chart

See Appendix E.

In addition, to the staff listed in the aforementioned organizational chart, the OCSHCN contracts and financially supports youth with special health care needs and families of children and youth with special needs to participate at all levels of decision making.

D. Describe how above contributes to ability to meet program expectations

The OCSHCN has an array of qualified professionals with expertise in management and organizational skills and outreach and community partnerships, including families and youth. Other areas include medical, social, statistical, and educational expertise. This multi-disciplinary team approach assures that the expertise and experiences of these highly qualified individuals are utilized in the planning, implementation and evaluations of all activities.

E. Describe proven leadership role

OCSHCN staff participates in leadership roles at the local, state and national level. Arizona is nationally recognized for providing leadership in many areas including strategies for financial reimbursement methodologies for c/yshcn, inclusion of youth and parents of c/yshcn as partners in decision making at all levels, development of parent led community teams, innovative methods for systems development, and collaboration of public/private partnerships for integration of services.

Our Office Chief Cathryn Echeverria speaks nationally at conferences and workshops and participates and serves on board of directors and advisory boards. She is known for her leadership in financing healthcare for special needs populations and has recently been asked to serve on a committee for Boston University School of Public Health as they are funded as a National Center on Health Insurance and Financing for CSHCN. She also serves as our state liaison with federal, state and local projects related to improving the systems of care for C/YSHCN. Recently, Cathryn was invited by the Child, Adolescent, and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration and the U.S. Department of Health and Human Services and the Technical Assistance Partnership for Child and Family Mental Health to participate in a working meeting on linking the medical home model with mental health systems. She also participates on the 2010 Leadership States Committee headed by Merle McPherson. Cathryn along with other OCSHCN staff serve as ADHS representatives on the Governor's Universal Application Process, the Arizona Transition Leadership Team, and the Community Development Interagency Initiative.

Jacquilyn Cox, (title) was the Senior Healthcare Researcher on the Health Outcomes Survey conducted by the Centers for Medicare & Medicaid Services with seniors enrolled in HMOs throughout the United States. Jacquilyn maintains relationship with the academic community through faculty appointments at Arizona State University Department of Psychology and the W. P. Carey Business School, Health Management and Policy. Barbara Hess, Systems of Care Manager, serves on many local and state committees and currently is a representative on the AzEIP Interagency Coordinating Council and the Infant Toddler Mental Health board.

Judie Walker, Education and Advocacy Manager serves as one of the Arizona Family Voices representatives and serves on their data team. She has 18 years experience of working with families who have children with special health care needs. As the former Arizona Parent Training and Information and Parent-to-Parent Project Director she has served on Arizona's original Interagency Coordinating Council, the UCP and TASH board of directors, as well as the local school district special education parent advisory team for 10 years. She has been a keynote speaker on issues related to inclusion of children with special needs and developed family-centered curriculum for physicians and other professionals who work with families and children with special needs.

Todd Lewis, M.Ed. has presented on a national web cast for Title V directors on transition issues and serves as our State Adolescent Health Coordinator. He has developed Student Led I.E.P. curriculum with Interact of Arizona, the state recipient of the Systems Change Grant, as well as partnering with youth and parents to develop a Parent/Youth Leadership Institute. Todd is also a faculty member at Mesa Community College and was a Special Education Teacher and Program Director for 5 years.

Relationship of Project to the Healthy People 2010 Initiative

In order to attain the Healthy People 2010 objective of community based systems of services in Arizona, children and youth must have access to medical homes, must be adequately insured, and must be screened for special needs on a regular basis. There must be concerted efforts, at the community level, to develop systems of services that families can use easily and in which they are actively involved as partners. Also, this system must ensure that youth with special health care needs are assisted in making a successful transition to adult health care, work, and independence. Thus, the Healthy People 2010 objectives and the goals and objectives listed in section III of this proposal are intertwined; one cannot be accomplished without also accomplishing the other. Both plans outline a series of concrete, practical steps toward accomplishing a integrated, community-based systems of services for all children with special health care needs in Arizona.

Smoke-free Workplace Policy

Effective October 1, 2004, tobacco use in any form is prohibited in buildings, vehicles, facilities, and campuses owned, leased, or occupied by the Arizona Department of Health Services (Department). Tobacco use by employees at the Arizona Department of Health Services' main campus is limited to areas outside of the perimeter of the campus.

ADHS/OCSHCN will further require all subcontractors, hosting agencies, and meeting locations to provide a smoke-free environment.

Accommodations for Disabled Adults and Youth

In accordance with the OCSHCN mission and the American's with Disabilities Act (ADA), OCSHCN will provide resources to pay for accommodations requested by families and youth with special needs. These accommodations would be those deemed necessary by the participant to fully engage in the proposed activities. Including, but not limited to: translation services; physical adaptations or modifications of work/meeting environments; transportation costs beyond the state mileage rate; and personal support staff. Statewide videoconferencing will be used for many of the activities to minimize travel, resources and extended time away from their communities. This will guarantee a statewide representation from all of Arizona's communities.

OCSHCN will contract with Pilot Parents of Southern Arizona (PPSA) to coordinate these services. Pilot Parents of Southern Arizona, the Partners in Policymaking program administrators, have agreed to assist us in making the arrangements for these types of accommodations. They have years of experience and established relationships with providers of these services. Currently, PPSA is contracted by OCSHCN and will provide in-kind dollars in their budget to administer and coordinate these services for the Integrated Systems Grant.

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XI. Appendices

Appendix A: Tables

Table 1

Arizona

Total Population of Children and Youth with Special Health Care Needs, 0-17 years old*

Prevalence Statistics			Indicator		
Child-Level Prevalence:			Impact on Child Health:		
	State %	Nation %		State %	Nation %
Percentage of Children & Youth with Special Health Care Needs, 0 - 17 yrs old	10.8	12.8	1) % of C/YSHCN whose health conditions consistently and often greatly affect their daily activities.	22.8	23.2
Household-Level Prevalence:			2) % of C/YSHCN with 11 or more days of school absences due to illness.	15.2	15.8
Percentage of Households with Children that have one or more C/YSHCN, 0 - 17 yrs old	17.8	20.0	3) % of C/YSHCN currently uninsured.	5.1	5.2
Prevalence by Age:			4) % of currently insured CYSHCN with coverage that is not adequate.	30.4	33.8
Children 0-5 years of age	5.5	7.8	Access to Care:		
Children 6-11 years of age	12.0	14.6	5) % of C/YSHCN with 1 or more unmet needs for specific health care services.	19.1	17.7
Children 12-17 years of age	15.0	15.8	6) % of C/YSHCN whose families needed but did not get all respite care, genetic counseling and/or mental health services.	23.1	23.1
Prevalence by Sex:			7) % of C/YSHCN needing specialty care who had problems getting a referral.	25.6	21.9
Female	8.4	10.5	8) % of C/YSHCN without a usual source of care (or who rely on the emergency room).	8.3	9.3
Male	13.1	15.0	9) % of C/YSHCN without a personal doctor or nurse.	11.8	11.0
Prevalence by Poverty Level:			Impact on Family:		
0% - 99% FPL	8.2	13.6	10) % of C/YSHCN whose families pay \$1,000 or more in medical expenses per year.	8.6	11.2
100% - 199% FPL	10.0	13.6	11) % of C/YSHCN whose families experienced financial problems due to child's health needs.	18.3	20.9
200% - 399% FPL	13.0	12.8	12) % of C/YSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child.	11.7	13.5
400% FPL or greater	12.3	13.6	13) % of C/YSHCN whose health needs caused family members to cut back or stop working.	30.3	29.8
Prevalence by Race/Ethnicity:					
Hispanic	6.8	8.5			
White (non-Hispanic)	13.8	14.2			
Black (non-Hispanic)	16.0	13.0			
Multi-racial (non-Hispanic)	17.8	15.1			
Asian (non-Hispanic)	4.4			
Native American/Alaskan Native (non-Hispanic)	5.7	16.6			
Native Hawaiian/Pacific Islander (non-Hispanic)	9.6			

* Weighted Estimates

**** Prevalence data only available for States where this minority group makes up at least 5% of total population of children in the State.

Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001.

Table 2

National Survey of Children with Special Health Care Needs, 2001		
National Outcome Measures*		
Outcome Measures	Arizona % (S.E.)	National % (S.E.)
Outcome #1: Families of CSHCN will partner in decision-making and will be satisfied with the services they receive.	51.4 (4.6)	57.5 (0.8)
a. Doctors usually or always make the family feel like a partner	82.2 (3.7)	84.3 (0.7)
b. Family is very satisfied with services received	54.4 (4.6)	60.1 (0.8)
Outcome #2: CSHCN will receive coordinated ongoing comprehensive care within a medical home.	50.5 (2.6)	52.6 (0.5)
a. The child has a usual source of care	91.2 (1.3)	90.5 (0.3)
I. The child has a usual source for sick care	91.7 (1.2)	90.6 (0.3)
II. The child has a usual source for preventive care	98.4 (0.5)	98.8 (0.1)
b. The child has a personal doctor or nurse	88.2 (1.5)	89.0 (0.3)
c. The child has no problems obtaining referrals when needed	74.4 (2.7)	78.1 (0.6)
d. Effective care coordination is received when needed	30.5 (6.2)	39.8 (1.5)
I. The child has professional care coordination when needed	84.0 (4.9)	81.9 (1.1)
II. Doctors communicate well with each other	53.7 (8.8)	54.4 (1.5)
III. Doctors communicate well with other program	25.3 (6.7)	37.1 (1.6)
e. The child receives family-centered care	63.7 (2.6)	66.8 (0.5)
I. Doctors usually or always spend enough time	82.3 (2.2)	83.6 (0.4)
II. Doctors usually or always listen carefully	87.3 (1.7)	88.1 (0.3)
III. Doctors are usually or always sensitive to values and customs	83.9 (1.9)	87.0 (0.4)
IV. Doctors usually or always provide needed information	79.0 (2.1)	81.0 (0.4)
V. Doctors usually or always make the family feel like a partner	84.9 (1.9)	85.9 (0.4)
Outcome #3: Families of CSHCN will have adequate private and/or public insurance to pay for the services they need.	60.8 (2.5)	59.6 (0.5)
a. The child has public or private insurance at time of interview	94.9 (1.1)	94.8 (0.2)
b. The child has no gaps in coverage during the year prior to the interview	86.4 (1.9)	88.4 (0.3)
c. Insurance usually or always meets the child's needs	86.7 (1.7)	85.5 (0.4)
d. Costs not covered by insurance are usually or always reasonable	75.4 (2.1)	71.6 (0.5)
e. Insurance usually or always permits child to see needed providers	86.0 (1.7)	87.8 (0.4)
Outcome #5: Community-based service systems will be organized so families can use them easily.	70.9 (4.2)	74.3 (0.7)
a. Services are usually or always organized for easy use	70.9 (4.2)	74.3 (0.7)

* Weighted Estimates

S.E. – Standard Error

Note: Shaded estimates do not meet the NCHS standard for reliability or precision. The relative standard error is greater than or equal to 30%.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001.

Table 3

National Survey of Children with Special Health Care Needs, 2001

Specific Health Care Services Needed*

Specific Health Care Services	Arizona (%) (95% C.I.)	Nation (%) (95% C.I.)
Routine Preventive Care	69.5 (64.6 - 74.4)	74.4 (73.6 - 75.2)
Specialist Care	48.0 (43.0 - 53.0)	51.0 (50.1 - 52.0)
Dental	73.9 (69.2 - 78.5)	78.2 (77.4 - 79.0)
Prescription Medication	88.0 (84.7 - 91.4)	87.9 (87.2 - 88.5)
PT/ OT/ Speech	22.5 (18.2 - 26.9)	23.5 (22.7 - 24.4)
Mental Healthcare Counseling	27.2 (22.6 - 31.8)	25.4 (24.5 - 26.2)
Substance Abuse	4.3 (1.2 - 7.3)	2.8 (2.5 - 3.1)
Home Healthcare	6.7 (3.9 - 9.5)	5.4 (4.9 - 5.8)
Vision Care – Eyeglasses	33.6 (28.9 - 38.3)	35.6 (34.7 - 36.4)
Hearing Aids or Care	8.4 (5.1 - 11.7)	6.5 (6.0 - 6.9)
Mobility Aids or Devices	4.9 (2.8 - 6.9)	4.7 (4.3 - 5.1)
Communication Aids/ Devices	2.6 (0.4 - 4.7)	2.1 (1.8 - 2.4)
Disposable Medical Supplies	25.4 (21.1 - 29.6)	24.9 (24.1 - 25.6)
DME	10.3 (7.8 - 12.8)	10.6 (10.0 - 11.1)
Genetic Counseling	5.1 (3.5-7.4)	6.9 (6.4-7.4)
Respite Care	8.0 (5.6-11.1)	8.8 (8.3-9.4)
Professional Care Coordination	12.0 (9.0-15.9)	11.8 (11.2-12.4)

* No significant difference between Arizona and National data

Table 4

National Survey of Children with Special Health Care Needs, 2001 Unmet Need for Specific Health Care Services* (Health care services needed but not received)		
Specific Health Care Services	Arizona (%) (95% C.I.)	Nation (%) (95% C.I.)
Routine Preventive Care	3.5 (1.4 – 5.5)	3.2 (2.7 – 3.7)
Specialist Care	9.5 (5.3 – 13.6)	7.2 (6.4 – 8.1)
Dental	10.0 (7.0 – 12.9)	10.4 (9.6 – 11.1)
Prescription Medication	1.1 (0.3 – 1.8)	1.7 (1.4 – 2.0)
PT/ OT/ Speech	15.3 (8.4 – 22.1)	11.1 (9.8 – 12.4)
Mental Healthcare Counseling	20.3 (13.2 – 27.4)	18.1 (16.5 – 19.7)
Substance Abuse	16.2 (0.0 – 36.8)	20.8 (16.1 – 25.5)
Home Healthcare	9.7 (0.0 – 19.9)	9.7 (7.0 – 12.4)
Vision Care – Eyeglasses	4.4 (1.4 – 7.4)	5.8 (5.0 – 6.5)
Hearing Aids or Care	15.2 (0.0 – 36.5)	9.2 (6.7 – 11.6)
Mobility Aids or Devices	3.6(0.0 – 9.5)	9.0 (6.0 – 12.0)
Communication Aids/ Devices	62.3 (22.5 – 100.0)	24.7 (18.1 – 31.3)
Disposable Medical Supplies	0.6 (0.0 – 1.5)	2.5 (1.9 – 3.2)
DME	2.4 (9.7-37.5)	4.7 (3.6-6.1)
Genetic Counseling	20.2 (9.7-37.5)	19.5 (16.6-22.7)
Respite Care	18.5 (10.0-31.8)	24.3 (21.5-27.3)
Professional Care Coordination	16.0 (8.5-28.1)	18.1 (15.9-20.4)

* No significant difference between Arizona and National data

Table 5

National Survey of Children with Special Health Care Needs, 2001				
Logistic Regression				
Independent Variables (Reference Category)	Family Partnership Core Outcome# 1	Medical Home Core Outcome# 2	Insurance Core Outcome# 3	Community-based Services Core Outcome# 5
Race (White)				
Black	1.33 (0.31-5.61)	0.27 (0.10-0.72)	4.04 (1.60-10.16)	0.73 (0.16-3.35)
AI/AN	0.48 (0.05-4.25)	0.32 (0.22-3.07)	0.83 (0.22-3.07)	0.14 (0.02-1.09)
Multiracial	1.17 (0.13-10.18)	1.10 (0.38-3.10)	1.50 (0.54-4.12)	3.33 (0.34-32.40)
Other	0.46 (0.00-1.94)	0.61 (0.30-1.26)	1.16 (0.62-2.16)	1.19 (0.39-3.58)
Ethnicity (non-Hispanic)				
Hispanic	0.38 (0.16-0.89)	0.83 (0.53-1.31)	0.63 (0.40-0.97)	0.98 (0.43-2.26)
Age (0-3 yrs)				
4-9 yrs	0.87 (0.26-2.88)	1.78 (0.91-3.47)	1.40 (0.72-2.70)	0.44 (0.11-1.80)
10-13 yrs	1.04 (0.30-3.53)	1.02 (0.50-2.04)	1.52 (0.75-3.07)	0.31 (0.08-1.26)
14-18 yrs	1.40 (0.42-4.66)	1.85 (0.93-3.67)	1.71 (0.87-3.36)	0.84 (0.21-3.34)
Mother's education (Less than high school)				
High school	4.04 (0.99-16.46)	1.08 (0.49-2.38)	0.85 (0.41-1.79)	1.63 (0.41-6.52)
More than high school	8.79 (2.42-31.82)	2.00 (0.98-4.11)	1.29 (0.68-2.46)	2.08 (0.63-6.85)
Gender (female)				
Male	0.97 (0.46-2.03)	0.85 (0.56-1.29)	1.10 (0.73-1.67)	0.80 (0.36-1.77)
Household Poverty level (<100%)				
100%-199%	7.32 (2.12-25.22)	1.33 (0.97-3.80)	1.62 (0.77-3.37)	2.49 (0.66-9.31)
>200%	5.27 (1.79-15.54)	1.92 (0.62-2.82)	2.55 (1.31-4.99)	3.77 (1.11-12.81)
MSA status (not in MSA)				
MSA	0.70 (0.17-2.85)	1.37 (0.67-2.81)	0.68 (0.35-1.34)	0.71 (0.18-2.79)
Insurance (private)				
Public	0.65 (0.23-1.82)	0.41 (0.23-1.72)	0.63 (0.35-1.15)	0.28 (0.10-0.80)
Other	0.44 (0.17-1.13)	0.63 (0.23-0.76)	1.36 (0.77-2.40)	0.65 (0.25-1.66)
Uninsured	2.38 (0.35-15.87)	0.4 (0.36-1.10)	0	0.72 (0.10-4.94)
Severity (least severe)				
Mild	0.49 (0.21-1.13)	0.85 (0.52-1.39)	0.76 (0.45-1.27)	0.43 (0.17-1.08)
Moderate	0.31 (0.11-0.86)	0.27 (0.15-0.47)	0.48 (0.26-0.87)	0.14 (0.04-0.41)
Most	0.62 (0.08-4.86)	0.06 (0.02-0.18)	1.01 (0.34-2.96)	1.87 (0.16-20.90)
Stability of health care needs (Usually stable)				
Change once in a while	0.74 (0.32-1.69)	0.68 (0.43-1.08)	0.54 (0.34-0.84)	0.28 (0.11-0.70)
Change all the time	1.27 (0.25-6.33)	0.28 (0.11-0.70)	0.81 (0.31-2.12)	0.38 (0.07-1.92)
None of the above	0	0.63 (0.03-10.39)	0	0

0 indicates some parameters tend to be infinity.

Appendix B: Job Descriptions of Key Personnel

ROLES AND RESPONSIBILITIES

Data, Planning, and Evaluation Manager

- Responsible for supervision and leadership of all teams relating to planning and evaluation
- Responsible for drafting proposed legislation and policy changes based on evaluation data
- Responsible for MCH Block Grant
- Responsible for organizing and conducting state and community wide needs assessments
- Responsible for analysis and reporting on assessment outcome
- Represent OCSHCN on external planning and policy teams to facilitate interagency collaboration
- Collaborate with other state agencies regarding implementation and analysis of findings from surveys/assessments conducted by the OCSHCN
- Responsible for annual Strategic Plan for OCSHCN in response to the Arizona Budget Reform Act
- Works with ADHS Information Technology staff and others to develop or alter management information systems

Research Analyst

- Establish and interpret office and agency implementation/evaluation of special projects related to the OCSHCN population
- Develop and implement policies and procedures for the application of epidemiological methods and practices for studies, projects, programs, and other related activities; provide analysis, interpretation and presentation of data as requested or required
- Provides technical assistance to internal and external entities regarding research and statistical analysis
- Develops methodologies for the surveillance of children and youth with special health care needs
- Analyze and report on national, state and community assessments

Health Program Manager III-Community Development

- Responsible for Parent and Community leader development, community development and system planning.
- Provide written reports and documentation of community development activities
- Provide team leadership to community teams to assure that goals and objectives of each team are met; technical assistance and consultation.
- Translation of information and resources as needed for community development activities.
- Collaboration with parents, communities and other agencies to develop a coordinated integrated system of care reform using the community development model.

Office Chief

- Systems planning, review and/or approve development and implementation of plans presented by staff
- Collaboration with other agency and organization staff to develop and implement coordinated system of care reform
- Supervise by directing, instructing and counseling staff in carrying out programmatic components
- Develop standards and quality assurance measures for system components
- Develop and implement policies and procedures for the Office
- Prepare and monitor budget, authorize budget expenditures and transfers

- Demonstrate knowledge and leadership in health care financing for c/yshcn.

Systems of Care Manager

- Representative to the State Interagency Coordinating Council
- Serve on the Infant Toddler Mental Health Coalition
- Maintain responsibility for development and management of Community Development, Community Nursing, Service Coordination, and Traumatic Brain Injury programs.
- Incorporate and integrate community development outcomes within a process to facilitate community, state and Federal level system change.
- Determine the need for preparation, support and implementation of legislation and IGA's appropriate for systems of care.

Education and Advocacy Manager

- Assess system of care issues and resources, and analyze education needs
- Develop, implement, and evaluate training on best practices for coordinated systems of care issues.
- Develop and expand Tele-health system for providing services for c/yshcn.
- Develop CME/CEU approved training and educational resources for professionals who serve c/yshcn in multiple formats including e-learning, videoconferencing, and face to face.
- Develop and manage the Medical Home, Transition, School Nursing, Asthma, Tele-health, Family/Youth Partnerships, and Physician Training Programs.

Medical Home and Transition Program Manager

- Develop recommendations and plans for improvement in meeting the indicators of medical home
- Organize, develop, and implement training programs and quality support with and for key stakeholders
- Develop resources, strategies and plans for ensuring the continuation of medical home activities in association with all areas of service for c/yshcn.
- Develop, implement, and evaluate transition activities for yshcn
- Develop training and evaluation tools to measure the effectiveness of the provision of services as defined by medical home including the transition of youth from pediatric to adult health care.

Business Operations Manager

- Responsible for leadership of all team and staff activities related to the fiscal operations for the Office for Children with Special Health care Needs within the Arizona Department of Health Services. Programs include Children with Special Health Care Needs through the Title V Maternal and Child Health Block Grant, Special Education under and allocation from the department of Economic Security, the Children's Rehabilitative Program which includes Title XIX and state funding.
- Responsible for providing sound financial short and long-range planning, fiscal and data management, office expenditure and receipts, cash flow, instituting internal monitoring procedures for Title XIX reimbursements, proving accurate data for contract negotiations, as well as encounter and financial reporting systems.
- Responsible for the design, implementation, and maintenance of appropriate accounting procedures and business processes.
- Responsible for the design, implementation, and maintenance of internal financial monitoring and procedures.

Community Parent Leader

- Participate in leadership development to enhance skills in the Community Development process, group facilitation, building consensus, etc.;

- Access to telephone and e-mail (check e-mails a minimum of 3 times weekly);
- Assist in the formation and ongoing initiatives of a Community Action Team;
- Facilitate communication by organizing meetings or calling upon identified citizens;
- Research existing groups in the community that may serve as partners;
- Develop partnerships with parents and professionals to assist children with special health care needs and their families;
- Provide technical assistance to working groups within the community;
- Identify and support the emergence of new Community Parent Leaders;
- Prepare and/or distribute written materials, as needed;
- Advocate for children with special health care needs within the community;
- Coordinate needs/resource assessment activities;
- Participate in focus groups and other evaluation activities as designed and requested;
- Facilitate the linking of Community Teams through conferences and trainings;
- Facilitate strategic planning and take action to resolve identified issues, utilizing internal and external resources;
- Promote community change, utilizing the OCSHCN Community Development Protocol and Elements of Community Development;
- Participate in state and national level meetings, conferences and workgroups to promote desired system change;
- Participate in the development and review of documents and provide feedback;
- Participate in OCSHCN sponsored activities, such as conference calls, meetings and conferences;
- Submit monthly documents including invoices, activity logs, Catalogs of Progress and other requested documentation, such as Community Team action plans;
- Perform other activities as may reasonably be requested by the community and/or OCSHCN.

Tsunami Parents



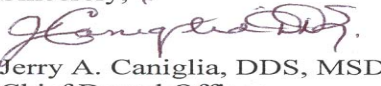

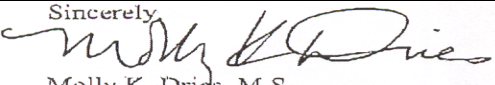




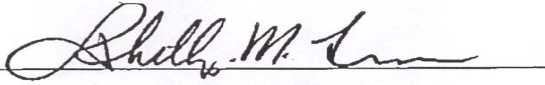

- Curriculum development
- Conference planning and presentations
- Block grant development and review
- Document development and review
- Web and resource committee
- Community nursing program
- Service coordinator program
- Representatives on committees and programs/projects
- Children's Rehabilitative Services
 - Quality Assurance site reviews
 - Parent Action Councils for Children's Rehabilitative Program (CRS)
 - Participate in quarterly medical director and administrator meetings
 - Guide policies and practice within four regional CRS clinics
- Parent/Youth Physician Interaction Project
 - Training provided by families and youth for physicians and other allied medical staff

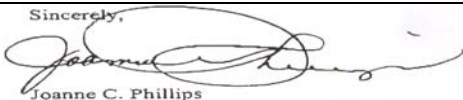


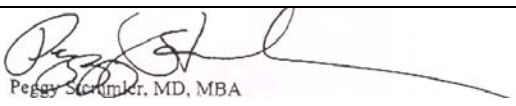
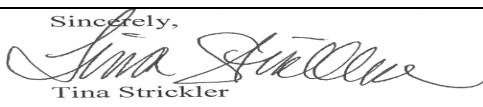
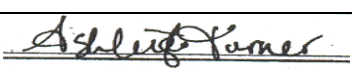
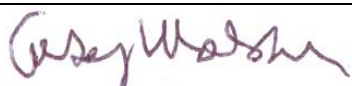

Appendix D: Letters of Recommendation and Participant Support

Chart 1

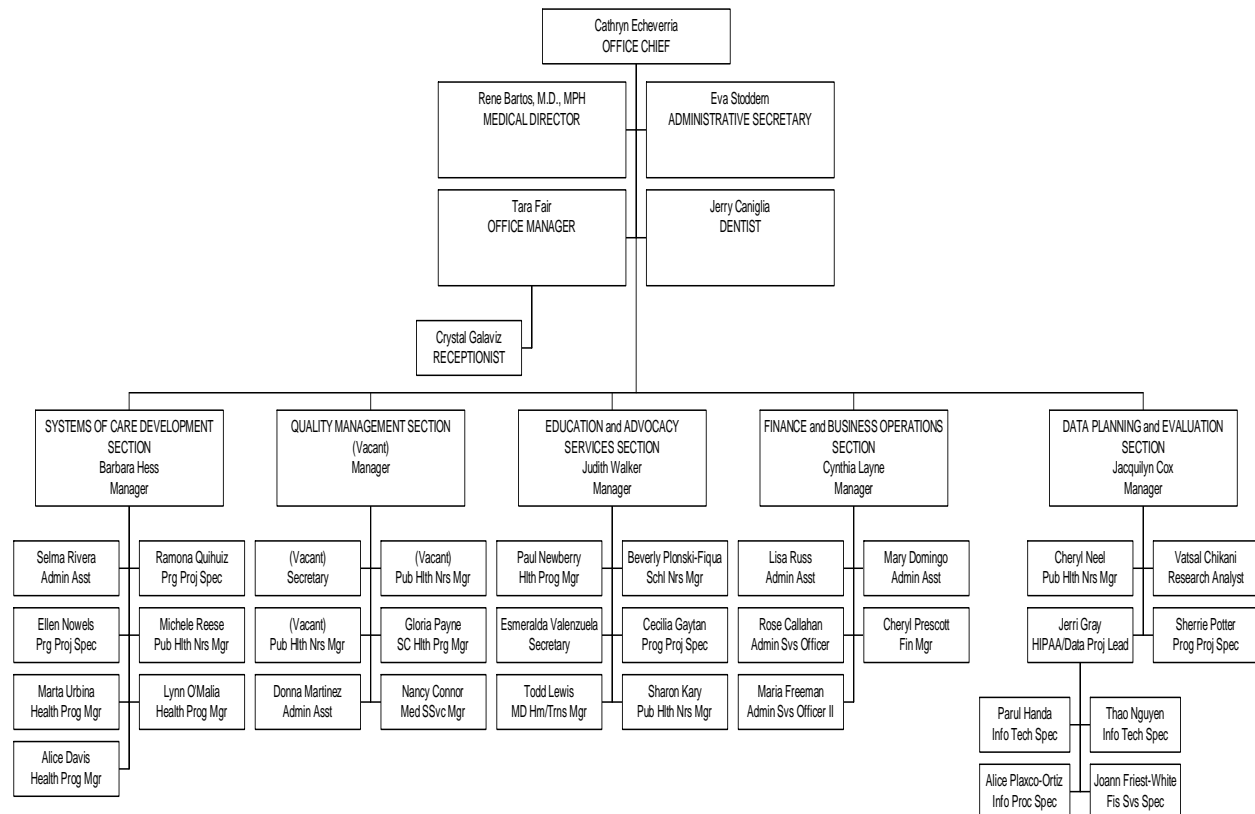
Participants in Community Planning Forum

Note: Asterisks indicates those participants who provided a letter of recommendation.

Participants	Signatures from Letters of Recommendations
Rita Aitken, Parent *	
Michael Allison * Native American Outreach Coordinator Arizona Department of Health Services	
Karen W. Burstein, PhD, Vice President Southwest Institute for Families and Children with Special Needs	
Jerry Caniglia, DDS, Dental Consultant * Arizona Department of Health Services, Office of Oral Health	 Jerry A. Caniglia, DDS, MSD Chief Dental Officer
Richard Carroll, PhD, Executive Director * Northern Arizona University Institute for Human Development	
Molly Dries, Executive Director * Department of Education Arizona Early Intervention Program Arizona Department of Economic Security	 Sincerely, Molly K. Dries, M.S.
Burris Duncan, MD * Professor of Pediatrics of Public Health University of Arizona	
Patti Hackett, Co-Director – Project Lead Healthy & Ready to Work National Center	
Becky Hamblin * Parent	
Linda Hamman * Parent	
Lynn Kallis, Executive Director * Pilot Parents of Southern Arizona	 Lynn Kallis, Executive Director Pilot Parents of Southern Arizona
Phil Lopes, Executive Director * AZ School-Based Health Care Council, Inc.	
Joyce Millard-Hoie, Executive Director* Raising Special Kids	 Sincerely, Joyce Millard-Hoie
Anu Partap, MD, MPH Director, Arizona Center for Community Pediatrics	

Joann Phillips * Deputy Associate Superintendent Department of Education	Sincerely,  Joanne C. Phillips
Frank Rider, MS, Chief of Children's Services Arizona Department of Health Services Behavioral Health Services	
Anthony D. Rodgers, Director * Arizona Health Care Cost Containment System	Sincerely,  Anthony D. Rodgers Director
Jeanette Shea-Ramirez Office Chief Arizona Department of Health Services Office of Women's & Children's Health	
Kneka Smith Arizona School of Dentistry & Oral Health	
Jami Snyder, Executive Director * Governor's Council on Developmental Disabilities	
Peggy Stemmler, MD, MBA * Stemmler & Associates President, Arizona Chapter American Academy of Pediatrics	 Peggy Stemmler, MD, MBA
Tina Strickler, Acting Office Chief * Arizona Department of Health Services Office of Oral Health	Sincerely,  Tina Strickler
Ashleigh Turner, Youth * Governor's Council on Spinal and Head Injuries	<u></u>
Dianne Wagemann Director of Policy Planning and Special Projects Division of Developmental Disabilities Division of Economic Security	
Casey Walker, Youth Coordinator * Arizona State University	
Ginger Ward, Executive Director Southwest Human Development	
Mary G. Warren, PhD, Senior Health Policy Analyst * State School Readiness Board	
Kim Yarbough, Director of Clinical Programs Arizona Association of Community Health Centers	

Appendix E: Project Organizational Chart



Appendix F: Other Relevant Documents

GLOSSARY OF ACRONYMS

AAP	American Academy of Pediatrics
ADA	American's with Disabilities Act
ADHS	Arizona Department of Health Services
AHCCCS	Arizona Health Care Cost Containment System
ASQ	Ages and Stages Questionnaire
ASU	Arizona State University
AzAAP	Arizona Chapter of the American Academy of Pediatrics
AzEIP	Arizona Early Intervention Program
BHS	Behavioral Health System
CRS	Children's Rehabilitative Services
C/YSHCN	Children and Youth with Special Health Care Needs
EMS	Emergency Medical Services
FPL	Family Poverty Level
HIPAA	Health Insurance Portability and Accountability Act
IEP	Individualized Education Plan
IGA	Inter-governmental Agreement
IHD	Institute for Human Development
IHS	Indian Health Services
MCHB	Maternal Child and Health Bureau
NAU	Northern Arizona University
PCAC	Parent Community Action Council
P-CAP	Pima County Access Program
PEDS	Parents' Evaluation of Developmental Status
PERT	Program Evaluation and Review Technique
SELECT	Special Education Learning Experiences Competency in Teaching
SLAITS	State and Local Area Integrated Telephone Survey
WIC	Women, Infants and Children Program
YAC	Youth Action Council
YSHCN	Youth with Special Health Care Needs